Human Immunodeficiency Virus Reporting by Non-Name Code:



A Manual for Health Care Providers and Laboratory Staff The following Office of AIDS staff have contributed to the development, and review of the curriculum, modules, information packets, powerpoint slides.

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Chapter

Introduction

Background on HIV reporting by non-name code in California and on how this manual is organized

HIV and AIDS Surveillance

On July 1, 2002, California joined the ranks of 48 other states that require reporting of human immunodeficiency virus (HIV). In California – as in 14 other states – HIV infections are reported using a non-name reporting system. (An additional 34 states have name-based HIV reporting systems.) This manual describes how California laboratories, health care providers, and local health departments can comply with the regulations that require HIV reporting.

The purpose of conducting public health surveillance is to determine ongoing patterns of disease occurrence and the potential for disease in a population. Agencies use surveillance data to describe and monitor health events in their jurisdictions; set priorities; and assist in the planning, implementation and evaluation of public health interventions and programs. The most well established systems for surveillance are usually those that monitor the occurrence of communicable diseases through required reporting by health professionals such as physicians and laboratories.

The use of health-related information for public health purposes is critically important for preserving, monitoring and improving population-based health as well as the personal health of individuals. HIV and Acquired Immunodeficiency Syndrome (AIDS) surveillance information serves as a scientific basis for programs and policies aimed at preventing and reducing the incidence of HIV infection, HIV-related conditions and death.

¹Georgia utilizes an anonymous reporting system and cannot match or unduplicate case reports.

²CDC. Diagnosis and Reporting of HIV and AIDS in States with HIV/AIDS Surveillance - United States, 1994 - 2000. MMWR 51(27);595-598.

Several sections of California's Health and Safety Code are relevant to HIV reporting. They include:

- Health and Safety Code, Section 120125 requires the California Department of Health Services (Department) to examine the causes of communicable disease occurring or likely to occur in the state.
- Health and Safety Code, Section 120130 authorizes the Department to establish a list of reportable communicable or non-communicable diseases and requires that the local Health Officer report those diseases to the Department.
- Health and Safety Code, Section 120140 authorizes the Department, upon being informed by a Health Officer of a contagious, infectious or communicable disease, to ascertain the nature of the disease and prevent its spread. To accomplish this, California Code of Regulations (CCR), Title 17, Division 1, Chapter 4, Subchapter 1, Article 1, Section 2500, subsection (b) directs health care providers to report diseases or conditions listed in subsection (j) to the local Health Officer.

AIDS Surveillance Data and its Limitations

Since the AIDS epidemic was first identified in the United States in 1981, population-based AIDS surveillance (reporting of AIDS cases and their characteristics to public health authorities for epidemiologic analysis) has been used to track the epidemic.

In 1993, national AIDS incidence and AIDS related deaths began to decline for the first time during the epidemic. Declines have been primarily attributed to the use of combination antiretroviral therapies, which delay the progression from HIV infection to an AIDS diagnosis and death. Prior to the emergence of effective drug treatment therapies for HIV infection, AIDS surveillance data was a reasonable, although not timely, method for detecting changing patterns of HIV transmission. AIDS surveillance data are currently used as a contributing factor to allocate federal resources for AIDS-related treatment and care services and as the epidemiologic basis for planning local HIV prevention and care services.

Changes in the medical standard of care for HIV-infected individuals have produced a delayed progression from HIV infection to AIDS diagnosis. As a result, AIDS surveillance statistics alone no longer reliably reflect the course of the epidemic or trends in HIV transmission, and are less useful for targeting HIV education, prevention and care efforts.

HIV and AIDS Surveillance in California

In California, individuals diagnosed with AIDS are reported by name to the public health authorities. AIDS case information for the state is maintained in the California Department of Health Services, Office of AIDS (DHS/OA) HIV/AIDS Case Registry – a confidential, central registry of demographic and clinical information. Registry staff collect data from local health departments throughout the state and forward the information, without personal identifiers, to the federal Centers for Disease Control and Prevention (CDC) as part of national AIDS surveillance.

Until July 2002, HIV infection without an AIDS diagnosis was not reportable in California. Lack of this information limited the state's ability to perform epidemiologic analysis to help monitor and project the extent of the HIV/AIDS epidemic, plan prevention strategies, and identify at-risk populations.

In December 1999, the CDC recommended that all states move to an HIV reporting system. While preferring a names based system, the CDC was supportive of code based systems as well. However, the CDC did establish certain minimum standards to be met by all systems.³

CDC Performance Standards for HIV Reporting

- HIV case reporting should be at least 85% complete
- At least two-thirds of the cases (66%) should be reported to the CDC within 6 months of diagnosis.
- Fewer than or equal to 5% of the cases can be duplicates or involve incorrectly matched case reports.
- At least 85% of HIV cases should have documented risk.

Benefits of HIV Surveillance

According to the CDC, states that report both HIV infection and AIDS have document-ed that the prevalence of those living with HIV infection, combined with those living with an AIDS diagnosis, provides a more realistic and useful estimate of the resources needed for patient care and services than AIDS data alone. The combination of HIV and AIDS surveillance data provides a minimum estimate of individuals known to be HIV-infected. These data do not represent total prevalence of HIV infection, for not all HIV-infected people seek testing. Others may test with home collection kits and many test at anonymous testing sites, which are not included in surveillance data. HIV case surveillance characterizes HIV-infected populations including persons with evidence of recent HIV infection such as infants, adolescents and young adults.

Statewide reporting of HIV infection in California will provide a strong basis for:

• prioritizing services for persons and communities in greatest need,

³CDC Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome. MMWR 1999; 48 [No. RR-13]

- setting evidence-based prevention priorities,
- understanding how prevention strategies influence disease trends,
- estimating future resource needs,
- comparing the allocation of funds with the distribution of the epidemic, and
- evaluating the effectiveness of public health prevention and treatment recommendations.

Future Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funding levels will hinge on California's ability to document the number of people living with HIV and AIDS.

Ryan White CARE Act Funding

Ryan White CARE Act funding addresses the unmet health needs of persons living with HIV disease by funding primary health care and support services that enhance access to and retention in care.

As with other states, CDC will provide technical assistance to DHS/OA to determine whether California's non-name code reporting system complies with Ryan White CARE Act performance standards.

California's HIV Reporting System

California's HIV surveillance system collects data for HIV cases using a non-name code. The non-name code is comprised of a number of elements used together to establish the 'uniqueness' of the code.

In California, individuals may choose to be tested for HIV in anonymous or confidential testing venues, both public and private. In accordance with Health and Safety Code Sections 120890-120895, free anonymous HIV antibody testing is available at Alternative Testing Sites (ATS) administered by local health departments. Anonymous testing is also available in some clinical settings other than an ATS, such as family planning and other health department clinics. Anonymous HIV testing maintains the anonymity of the patient because clients never disclose their names or any personally identifying information. Confirmed HIV test results for patients of an ATS or other anonymous HIV testing program, or a blood bank, donors at a plasma center, or participants of a blinded and/or unlinked seroprevalence study are not reported. In contrast to anonymous testing, public health programs also offer confidential HIV anti-body testing and can link the patient to the test result in a restricted manner that protects patient confidentiality. Confidential HIV tests sites are required to report confirmed HIV tests.

In addition to tests that confirm the presence of HIV antibodies, tests used to monitor HIV infection are also reportable such as viral load testing and viral cultures. The remainder of this training curriculum discusses which tests are reportable and how cases are to be reported by health care providers and laboratories.

AIDS vs. HIV Reporting in California

California's HIV reporting system is designed to track trends in the HIV epidemic while protecting the privacy of those who receive a confirmed HIV test result. The reporting process involves five separate parties: the health care provider who orders the test, the laboratory that performs the test, the local health department, the DHS/OA, and the CDC. The local health department, DHS/OA, and the CDC will not have a record of the name of the HIV-infected individual, only the case report with the non-name code.

An AIDS diagnosis is determined by the presence of HIV infection in conjunction with one or more specified opportunistic infections or clinical manifestations. Since 1983, AIDS cases have been reported by name to local health departments. In comparison, HIV infection is determined by the results of an HIV antibody test or tests used to monitor HIV infection. HIV tests are conducted by laboratories; therefore, laboratories are a vital link in the HIV reporting system. The HIV reporting regulations mandate laboratory reporting of confirmed HIV tests and correspond with current law that requires laboratories to report certain other communicable diseases to public health authorities. Laboratory reporting of HIV infection to the local health department will serve as a control for determining the total number of confirmed HIV tests in a jurisdiction, as well as the location of the health care provider that originates the test (for follow-up purposes).

Matching HIV Reports

Confirmed HIV tests (reported by laboratories) and HIV case reports (submitted by health care providers) will be matched a number of times throughout the reporting process to ensure that duplicate reports are discovered and eliminated. The local health department surveillance staff shall perform the first match by comparing the reported laboratory test result to the local HIV/AIDS database to determine if an HIV case report already exists.

The second match, also performed by the local health department, matches unduplicated laboratory test results to new HIV case reports previously submitted by health care providers. Potentially new cases will be checked against the statewide database by contacting DHS/OA HIV/AIDS Case Registry. The Registry then submits new cases to the CDC.

If duplicate reports from differing jurisdictions are discovered, DHS/OA staff will contact the two health departments and a determination will be made by the two local health departments as to where the individual was living at the time of the first confirmation of HIV infection.

Protecting Confidential Data

Local health departments and the DHS/OA securely store HIV case report data in a manner consistent with AIDS case reports. Data are stored in a computer database secured and isolated from outside contact, and paper files are in a locked file within a secured area.

About This Manual

The current regulations – Title 17, Division 1, Chapter 4, Subchapter 1, Article 3.5, Sections 2641.5-2643.2 of the California Code of Regulations (CCR) – describe the responsibilities of laboratories, health care providers, and local health departments in reporting HIV by non-name code. These responsibilities are described in greater detail in the remaining sections of this manual.

Chapter 2 provides an overview of the regulations themselves, including a matrix of each section's language and source, a flow chart showing who does what (and when), and key terms to know.

Chapter 3 covers the regulations that apply to health care providers.

Chapter 4 reviews the regulations that apply to laboratories. (Both chapters 3 and 4 offer step-by-step guidance on reporting requirements, recordkeeping, cross-reference systems, and special considerations unique to each entity.)

Chapter 5 sums up frequently asked questions about situations that may occur – such as missing data, multiple laboratories, test duplication, patients tested and living in different states, and so on.

ICON K	ΕΥ
	Reminders
	Regulations
	Forms
	Resources for more information

Throughout the manual, we have used several icons to highlight different types of information, as shown in this key.

For example:



For more information . . .

Visit the DHS/OA web site: www.dhs.ca.gov/AIDS. For more information on training events and materials, contact ETR Associates at www.etr.org/hivnonname.

The next chapter – Chapter 2 – introduces the regulations.

Chapter

The Regulations: An Overview

Highlights of the California Code of Regulations, Title 17, Division 1, Chapter 4, Subchapter 1, Article 3.5, Sections 2641.5-2643.20.

Regulations At-A-Glance

The regulations specifying how new HIV cases are to be reported are in California's Code of Regulations, Title 17. Entitled "Reporting of Human Immunodeficiency Virus (HIV) Infection," the regulations include definitions and specific reporting requirements for healthcare providers, laboratory staff and local health departments. Each of these steps is described in detail in the next two chapters, but for quick reference, we have provided the actual regulations in Appendix A.



The Regulations Say

In addition to Appendix A, specific **regulations** relevant to each section are provided throughout this guide. **They are marked with the symbol of an open book.**

The Reporting Process

A simple way to visualize the regulations is shown in the flow of information about HIV test results in Figure 2.1, below.

As Figure 2.1 demonstrates, the HIV reporting process is a laboratory-driven, **dual reporting system** in which health care providers and laboratories report to the local health department (a county or large city health department). The laboratory's finding of a confirmed HIV test result triggers the system. The local health department, in turn, reports cases to the DHS/OA, which then reports to the CDC. Although this process is specific to HIV, it is similar to the flow of information typical of other reportable diseases.

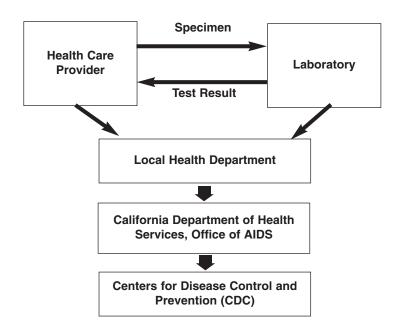


Figure 2.1: The Dual Reporting System for Non-Name HIV Reporting

At each step, the reporting entity has specific responsibilities to add information that will be used by local, state, and federal public health agencies to create unduplicated counts of HIV cases. More information on the forms and timelines required for each step will be provided in Chapters 3 and 4; a more detailed version of the flow chart is provided in Appendix B.

Speaking the Same Language: Terms to Know

Terms covered in this section:

- Health care provider
- Laboratory
- · Anonymous testing
- Confidential testing
- Confirmed HIV test
- Non-name code
- Confidential HIV Antibody Test Form
- HIV/AIDS Confidential Case Report form

Like other regulations, the success of California's HIV reporting system hinges on a common understanding of what is required from each entity. This section highlights some of the key terms used throughout the regulations. (For a full set of definitions, see the actual regulations in Appendix A.)

Who reports?

Who is covered by the regulations? The regulations cover three types of organizations: health care providers, laboratories, and public health agencies. The term "Health Care Provider," used throughout the regulations, refers to anyone who submits specimens to a laboratory for testing for the presence of HIV and receives the test results back from the lab. This includes not only clinicians in settings where people are tested for HIV (physicians, surgeons, nurses), but also counseling staff in publicly funded confidential HIV counseling and testing programs.



"Health Care Provider" means an individual who submits a biological specimen to a laboratory for a test to detect the presence of HIV, a component of HIV or antibodies to or antigens of HIV, receives the test results, and is:

- a) licensed under the provisions of Business and Professions Code, Division 2 (Healing Arts) and acting within his or her scope of practice, or;
- a designee of a physician and surgeon acting under the general supervision of that physician or surgeon, or;
- a person working in a publicly-funded confidential counseling and testing program acting under the general supervision of, and following the protocols approved by, the local Health Officer for the local health department.



"Laboratory" means a 'clinical laboratory,' a 'physician office laboratory,' or a 'public health laboratory,' as defined in Business and Professions Code, Section 1206, that is authorized to perform clinical laboratory tests or examinations in California, or a clinical laboratory located outside of the State of California that is licensed pursuant to Business and Professions Code Section 1241(a) and that tests specimens originating in California.

The term "laboratory" covers California laboratories that are authorized to perform clinical laboratory tests or examinations in California, such as clinical laboratories, laboratories in physicians' offices, and public health laboratories. Laboratories outside of California that are licensed to test specimens that originate in California are also subject to the reporting requirements.

Some individuals and entities are **exempt** from the HIV reporting regulations: anonymous HIV test sites (including Alternative Testing Sites), blood banks, plasma centers, and some research studies (such as blinded and/or unlinked seroprevalence studies).



"Anonymous HIV Test" means an HIV test that maintains the anonymity of the patient.

"Confidential HIV Test" means an HIV test that links the test results to the patient in a restricted manner to protect against unauthorized disclosure of the identity of the patient.

Anonymous vs. Confidential HIV Testing

The term "anonymous" in the context of HIV testing means that there is no link between the name of the person tested and the test results. Alternative and other anonymous test sites do not seek or receive any identifying information about their patients, so they are exempt from HIV reporting requirements.

In contrast, "confidential" testing means that a test result can be linked to a specific patient, but this link is restricted to persons involved in the diagnosis, care, or treatment of the patient and is not released further without patient consent so that the patient's identity is protected against unauthorized disclosure.



"Confirmed HIV test" means:

- a) a procedure that verifies the presence of HIV infection as determined by any clinical laboratory test or examination used to detect the presence of HIV, a component of HIV, or antibodies to or antigens of HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody tests; or
- b) for the purpose of this Article, all tests used to monitor HIV infection, including HIV nucleic acid detection.

What gets reported?

Which tests must be reported? HIV reporting is triggered when the laboratory determines a confirmed test for HIV. The term "confirmed HIV test" has a very specific meaning. It refers to a confirmed serology test that:

- Verifies the presence of HIV infection, a component of HIV, or antibodies to or antigens of HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody (IFA) tests; or
- Is used to monitor HIV infection, including HIV nucleic acid detection (e.g., viral load).

Note that a positive enzyme-linked immunoabsorbent assay (ELISA) test – even a series of several positive ELISA results – should not be reported unless it has been confirmed by Western blot or IFA. Similarly, tests that monitor drug resistance or fluctuations in T-cell counts should not lead to HIV reporting. (Note that a separate protocol is in place for reporting cases of AIDS.)

Note also that all viral load tests are reportable - even those with an "undetectable" result.



What Does NOT Get Reported?

Laboratories are *not* required to report findings from the following tests to the local health department:

Enzyme-linked immunoabsorbent assay (ELISA) or enzyme immunoassay (EIA)

CD4 or CD4/CD8 ratios

Drug resistance tests (genotypic, phenotypic)

What Is the Non-Name Code?

Instead of using names, the HIV reporting system relies on a code created from several existing pieces of information. This 17-digit code is essential for establishing an accurate, unduplicated case count. For this reason, it is critical that health care providers and laboratories thoroughly comply with the record-keeping aspects of the HIV reporting regulations.

The non-name code includes the following elements:

- A Soundex code. (Soundex is an algorithm that produces a four-digit code from the first letter and subsequent consonants of a person's last name, consisting of one letter and three numbers. Once it is generated, it cannot be used in the reverse direction to figure out a person's identity.)
- The patient's **date of birth** (in the format of mm/dd/yyyy e.g., 03/06/1963 for March 6, 1963).
- The patient's **gender** (1-male, 2-female, 3-transgender male-to-female, or 4-transgender female-to-male).
- The last four digits of the patient's Social Security Number. (If these are not available, four zeroes are used instead.)⁴

Partial Non-Name Code

The first three elements – Soundex code, date of birth, and gender – comprise a **partial non-name code** (i.e., one with all the elements except the last four digits of the Social Security Number).

The laboratory generates a Soundex code and returns the partial non-name code that corresponds to a specific *confirmed* HIV- test result back to the provider (along with the test result and the lab-generated report number). The provider then adds the last four digits of the patient's Social Security Number to the partial non-name code to create a 17-digit non-name code.



"Non-Name Code"
means a designation
required by Section
2643.5 of this Article,
that does not readily
identify an HIV-infected
individual. Components
of the Non-Name Code
shall be listed in the following order, and shall
consist of an individual's:

- a) Soundex code;
- b) Complete date of birth (2-digit month, 2-digit day, 4-digit year);
- c) Gender (male [1], female [2], trans gender male-to-female [3], or trans gender female-to-male [4]); and Last four digits of the Social Security Number (if not available, use four digits of zero).



"Soundex code" means a phonetic, alphanumerical formula that is used to convert the first letter and sequential consonants of an individual's surname into an algorithm. The Soundex code instructions are identified by the Department as form DHS 8641 SC (9/01), hereby incorporated by reference in this Article.

⁴ Every effort should be made to obtain the last four digits of a patient's Social Security Number. Patients should be reminded that these four digits cannot be linked to their identity.





"Partial Non-Name Code" means a designation required by Section 2643.10 of this Article, that does not readily identify an HIV-infected individual. Components of the Partial Non-Name Code shall be listed in the following order, and shall consist of an individual's:

- a) Soundex code;
- b) Complete date of birth (2-digit month, 2-digit day, 4-digit year); and
- c) Gender (male [1], female [2], transgender male-to-female [3], or transgender female-to-male [4]).

Comparison of Sample Non-Name Code and Partial Non-Name Code

Non-name Code: B2601024195227382

(17 digits: Soundex code, date of birth, gender, and last 4 digits of Social Security Number)

Partial Non-name Code: B260102419522

(13 digits: all of the above – Soundex, date of birth, and gender — *except* last 4 digits of Social Security Number)

The Paper Trail: HIV Non-Name Code Reporting Forms

The HIV reporting system incorporates some existing forms already familiar to health care providers and laboratories and adds some new ones. These are briefly summarized below and copies of each of the forms are provided in Appendix C.

Forms used by publicly funded testing sites, other providers, and laboratories are listed below. Features of different laboratory preprinted requisition forms are shown in Table 2.1.

Reporting entities: health care providers and laboratories

- Providers use a laboratory's preprinted requisition form to request an HIV test. The provider fills out an initial set of information (the patient's last name, date of birth, gender, date the specimen was collected, and the provider's name, address, and telephone number). This form accompanies the specimen to the laboratory, and if the test result is reportable, more information is added (test results, report number assigned by laboratory, and Soundex code).
- When a confirmed test is determined, the laboratory converts the last name to Soundex and provides the Soundex to the health care provider, along with the test result.
- Laboratories report to local health department HIV/AIDS Surveillance
 Programs by manual or electronic methods. The laboratory report may not
 include the patient's name but must include: patient's Soundex code, complete
 date of birth, gender, date specimen tested, name, address and telephone
 number of the provider and laboratory, laboratory findings of test performed
 and specimen report number assigned by the laboratory.
- For all positive test on patients not previously reported, health care providers complete adult (green) or pediatric (gold) HIV/AIDS Confidential Case Report forms (DHS 8641 A or 8641 P) and submit the completed form to their local health department HIV/AIDS Surveillance Program.

Publicly funded counseling and testing sites

- Publicly funded confidential HIV testing sites use a new red Confidential HIV
 Antibody Test laboratory slip (DHS 8257C (1/02)) to request an HIV test and
 to report confirmed results to local health departments. (The purple laboratory
 slips are for anonymous testing in anonymous test sites only, and do not trigger
 HIV reporting)
- Like other providers, publicly funded confidential HIV testing sites complete
 adult (green) or pediatric (gold) HIV/AIDS Confidential Case Report forms
 (DHS 8641 A or 8641 P) and submit the completed form to their local health
 department HIV/AIDS Surveillance Program.

Optional laboratory forms

• Laboratories using a paper-based reporting process may use the suggested model form entitled "Notification of Confirmed HIV Test Result by Laboratory to Local Health Department" to report. (A copy of the suggested paper report from and information on submitting confirmed HIV test results electronically is provided in Appendix F.)



Table 2.1: Laboratory Preprinted Requisition Forms						
Form: Laboratory preprinted Antibody Test form		Red Confidential HIV Antibody Test form (DHS 8257C (1/02))	Purple Anonymous HIV Antibody Test form (DHS 8257A (1/02))			
Used by:	Health Care Providers, some publicly funded HIV counseling and testing (C&T) sites	Majority of publicly funded confidential HIV C&T sites ATS, other anonymou publicly funded HIV C&T sites				
Specimen report number as assigned by the laboratory	number as assigned the laboratory or other 8		California DHS/OA 8-digit client ID number			
Should a confirmed HIV test be reported to the health department? Yes, unless the specimen came from an exempted site		Yes	No			

Chapter

Health Care Providers: Step-by-Step HIV Reporting

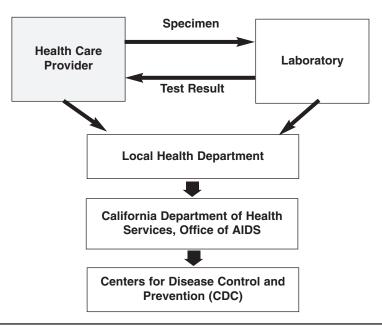
How providers participate in the HIV reporting system

Step 1: Setting Up A Reporting Protocol

When a California resident is tested for HIV, the provider who submits the specimen to a laboratory for testing and receives the confirmed test results from the laboratory is responsible for reporting to the local health department. (Note that this definition includes counselors at confidential HIV counseling and testing sites.)

Figure 3.1, below, shows the health care providers responsibility in the HIV non-name code reporting process.

Figure 3.1: The Dual Reporting System for Non-Name HIV Reporting



The first step for a health care provider is to set up a protocol for the reporting responsibilities, including designating a staff member to be responsible for reporting HIV cases to the local health department. This person should work directly with the provider's local health department to assure that cases are reported accurately and within the time frames required by the regulations. If necessary, providers should contact their local health departments for assistance in establishing a protocol.

As described below, the steps a protocol should cover include forwarding specimens and the laboratory's preprinted requisition slips to the laboratory, adding the last 4 digits of a patient's Social Security Number to create a non-name code, completing and forwarding HIV Confidential Case Report forms to the local health department, and maintaining a cross-referencing system to track tests and results to facilitate communication with surveillance staff.

Step 2: Specimen and Laboratory Slip to Laboratory

On the laboratory's preprinted requisition slip,⁵ the provider records the following information to accompany the blood specimen to the laboratory:

- The date the specimen was collected (mm/dd/yyyy)
- The patient's last name
- The patient's gender (male, female, transgender male-to-female, or transgender female-to-male, as reported by the patient)
- The patient's complete date of birth (mm/dd/yyyy)
- The health care provider's name, address, and telephone number and the clinic's or facility's name, address, and telephone number (if different from the provider's).



Recording Surnames (Last Names)

Some clients may use two last names or hyphenated names. If this is the case, please enter both last names as one word in the "surname" box on both the laboratory slip, omitting hyphens. Since Soundex codes are created from surnames, we can only be sure of unduplicated reports of HIV cases if the names are recorded consistently and accurately.

⁵ Publicly funded confidential HIV counseling and testing sites may use the red "Confidential HIV Antibody Test" laboratory slip (DHS 8257C (1/02)). The red laboratory slip is a new form to be used for confidential HIV testing only. It replaces the purple form that was used before July 1, 2002 for both confidential and anonymous HIV tests. Since July 1, 2002, when the HIV reporting regulations went into effect, the purple form is used only for anonymous testing (which does not require reporting of confirmed HIV test results).

Once the laboratory receives the specimen from a health care provider, tests the specimen, and obtains a confirmed HIV test result, the laboratory begins its own portion of the reporting process. (The laboratory's specific reporting requirements are discussed in greater detail in Chapter 4. Samples of the laboratory's preprinted requisition slips are provided in Appendix C.)

The provider must receive confirmed HIV test results from the laboratory within 7 calendar days of the laboratory's final determination. The laboratory must also supply the provider with the following additional information:

- Test results;
- Soundex code that the laboratory creates from the patient's last name; and

Note that the Soundex code, when combined with the date of birth and gender, forms the partial non-name code. The provider will complete the code by adding the last four digits of the patient's Social Security Number and record this 17-digit non-name code on the Confidential Case Report form, as described below.

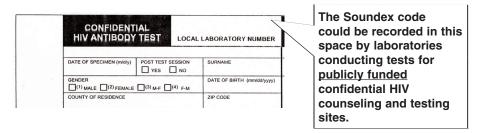


Where is the Soundex code?

Current laboratory reports to health care providers may not include a specific labeled spot for entering the Soundex code. This is the 4-digit code (1 letter and 3 numbers) that will be transferred by the health care provider to the "Soundex code" boxes on the Confidential Case Report forms (discussed in the next step). Laboratories should determine an appropriate empty space where the code will be entered and clarify the field for the provider.

For example, the current version of the red laboratory slip (Confidential HIV Antibody Test – DHS 8257C, 1/02) for publicly funded HIV confidential counseling and testing sites does not include a specific, labeled spot for entering the Soundex code. Laboratories will be asked to enter the code in the empty space just above the patient's surname or make arrangements with the local health department counseling and testing coordinator.

Publicly Funded Confidential Test Sites



Step 3: Reporting to Local Health Departments

After receiving a positive test result on a previously unreported individual from the laboratory, the health care provider has 7 calendar days to complete the Confidential HIV Case Report Form and send it to the local health department. If the provider, patient, and laboratory are located in different places, health care providers should forward information about new HIV cases to the local health department in which the *provider's office* is located or the service was provided – not where the patient lives or the laboratory is located.

Completing the Confidential Case Report Form

Providers report HIV cases to their local health departments using adult (green) or pediatric (gold) **HIV/AIDS Confidential Case Report** (DHS 8641 A (9/01) or DHS 8641 P (9/01)). Samples of completed forms are provided in Appendix C.

Table 3.1, below, lists the information required by each section of the form.

	Adult		Pediatric		
I.	Health Department Use	I.	Health Department Use		
II.	For HIV and AIDS Cases;For Non-AIDS Cases Only	II.	For HIV and AIDS Cases; For Non-AIDS Cases Only		
III.	Demographic Information	III.	Demographic Information		
IV.	Facility of Diagnosis	IV.	Facility of Diagnosis		
V.	Patient History	V.	Patient/Maternal History		
VI.	Laboratory Data	VI.	State/Local Use		
VII.	State/Local Use	VII.	Laboratory Data		
VIII.	Clinical Status	VIII.	Clinical Status		
IX.	Treatment/Services Referrals	IX.	Provider information		
X.	Comments	X.	Birth History		
XI.	Provider Information	XI.	Treatment/Service Referrals		
		XII.	Comments		

Except for the sections on maternal risk and birth history on the pediatric version, both adult and pediatric HIV Confidential Case Report forms request similar information. In order to complete them, providers should collect as much risk factor information as possible before ordering the HIV test. Documenting risk factors is an important part of California's efforts to target educational and prevention efforts. Additionally, federal Ryan White CARE Act funding will depend on the state's ability to document valid risk information on at least 85% of individuals with reported positive tests.

A sample of a complete Confidential Case Report form can be found in Appendix C.



To make completion of the Confidential Case Report forms as efficient and accurate as possible, the DHS/OA recommends the following:

- Identify and assign a staff member to be responsible for HIV reporting.
- Assure that all information necessary to complete the Confidential Case Report form is available to the staff member:
 - Risk documented
 - Surname
 - · Date of birth
 - Social Security Number (or last 4 digits)
 - Type of test
 - Dates specimen ordered, collected
 - Date laboratory returned test result

After entering the date on which the form is completed (in the upper left-hand corner), the first entries for providers will occur in Section II of the Confidential Case Report form, shown below.

Section II of HIV/AIDS Confidential Case Report

II. For HIV a	ind AIDS Cases		For Non-AID	S Cases Only	
Soundex Code	Date of birth	Gender	Last four digits of SSN	Lab report number	*Confidential C&T number
	Month Day Year	1 M 3M→F 2 F 4F→M			*Publicly landed confidential counseling and testing siles only

Section II asks for the following information:

- Soundex code (provided by the laboratory)
- Date of birth
- Gender
- Last four digits of the patient's Social Security Number
- Specimen report number assigned by the laboratory.



What if the Social Security Number is not available?

Providers should make every attempt to obtain correct Social Security Number digits to assist local health departments in creating a reliable database for matching and

unduplicating HIV case reports. The last four digits of a patient's Social Security Number cannot be used to trace him or her. However, if the patient's Social Security Number is not available, enter four zeroes instead.

The combination of a Soundex code, date of birth, gender, and last four digits of the patient's Social Security Number creates the **17-digit non-name code** that local and state public health authorities will use to make sure HIV cases are not duplicated (e.g., from multiple tests or multiple providers). For this reason, accurate information is essential. Likewise, to maintain consistency and accuracy, the HIV reporting regulations require that laboratories – not providers – generate the Soundex code.

Note that the HIV/AIDS Confidential Case Report form is to be used when reporting a new case of HIV to the local health department. The same form is required for reporting an AIDS case at the time of an AIDS diagnosis, using the appropriate sections of the form, even if someone has previously been reported as an HIV case.



Need help with the Confidential Case Report?

Technical assistance is available for health care providers. Contact your local health department.

Maintaining a Cross-Referencing System

A cross-referencing system allows <u>health care providers</u> to quickly access information on reportable HIV cases. Such a system is required by the HIV reporting regulations and must include either the complete Non-Name code or the partial Non-Name code. It can save valuable time and resources in those instances in which the local health department needs to track down missing information or investigate possible duplicate reports.

A cross-referencing system is also useful for providers themselves, since providers may receive multiple laboratory reports confirming HIV or viral load results. With a cross-referencing system, providers can make sure that they report each HIV case to their local health department only once.

The DHS/OA has prepared an example that can be used for cross-referencing HIV cases by the available data elements – whatever they may be. This format, presented in Appendix D, is offered as a potentially time-saving suggestion that will help everyone involved in the new non-name reporting system when missing data must be found.

It is suggested that the following elements be included:

- Patient's name (last name, first name)
- Medical record number
- Soundex code
- Date of birth (mm/dd/yyyy)
- Gender
- Social Security Number (last four digits)
- Report number assigned by laboratory
- Laboratory name
- Date HIV reported to local health department
- Date AIDS reported
- Comments

Sample Cross-Reference System								
Patient's name Last, First)	Medical record #	Soundex code	Date of Birth (mm/dd/yyyy)	Gender	SSN (Last 4 digits)	Lab-generated Report #	Lab Name	Date HIV reported to LHD
Smíth, John	021145	S530	05/25/82	male	9092	123456789Q	Heath Srvs Agency	10/03/02

Special Considerations for Providers and their Patients

Because of their direct contact with the patients being tested for HIV, health care providers may be faced with questions and concerns about confidentiality and obtaining informed consent.

Confidentiality

The non-name HIV reporting system is designed to balance the need to maintain unduplicated records of HIV cases with concerns about managing a database that contains patient information. Because a code is used instead of a name, the patient's name can never be reported to the local health department, state, or CDC. Likewise, only the last four digits of a patient's Social Security Number are used. These cannot be traced back to a name; they are used only to differentiate one HIV test result from another.

Information about patients is confidential and is securely stored. The information that the provider and laboratory collect with the patient's name – such as a laboratory slip – is never forwarded to health authorities with the name still attached.

Free, anonymous HIV testing remains available as an option to or alternative to confidential HIV testing. However, a patient who tests positive in an anonymous test site will ultimately be reported at the time of treatment.

Consent

In most testing settings – such as a private physician's office or a hospital – consent procedures may involve oral consent only. In some situations, consent for an HIV test is not required. This is true of court-ordered HIV tests.

Publicly funded HIV counseling and testing sites follow a specific consent protocol and obtain written consent using a "Consent to Test for HIV" form.

Talking Points

Talking points for communicating with your patients about the regulations can be found on the next page.



Talking Points to Patients About HIV Non-Name Code Reporting

- HIV is reportable by a non-name code, created from the patient's last name, date of birth, gender, and last four digits of his or her Social Security Number. This assures reliable data while protecting patients' confidentiality.
- It is highly unlikely that the code can ever be used to work backwards and reveal the patient's identity.
- Anonymous testing is available from publicly funded sites for patients who would prefer it.
- All patient information is confidential.
- A positive patient's name is not reported. The reporting indicates
 that a new case of HIV has been diagnosed. Identifying
 information Soundex code, birthdate, gender, and last four
 digits of the Social Security Number is used solely to ensure
 that reported cases are distinct from one another.
- Accurate HIV reporting is important to allow California to receive federal HIV and AIDS funding.
- Notifying patients about HIV reporting is not required by the regulations. Whatever protocol is used for informing patients about reporting other communicable diseases could be followed for HIV reporting.

Summary

- Health care providers must report confirmed HIV test cases. This includes anyone who submits a biological specimen to a laboratory to be tested for HIV, receives the test results, and is either licensed under the provisions of the Business and Professions Code, Division 2 (doctors, osteopaths, coroners, physician assistants, nurse practitioners, and so on) or acts under the general supervision of a physician and surgeon, or works in a publicly funded confidential counseling and testing program that follows the local health department protocols.
- Health care providers must submit specific information. First, they obtain
 specific information from their patients when a laboratory test is ordered and
 submit that information to laboratories on the laboratory's preprinted
 requisition slips, along with the specimen to be tested for HIV.
- Upon receipt of a confirmed HIV test result from the laboratory, health care providers have 7 calendar days to complete a pediatric or adult Confidential HIV/AIDS Case Report form and forward it to their local health department. The combination of information from the laboratory and information added by the health care provider creates the non-name code that the local health department uses to assure unduplicated reporting of cases.
- It is required that health care providers maintain a system that cross-references
 patient data, including non-name code elements, to assist them in answering
 questions about reported cases.
- Health care providers should assess and document patient risk behaviors before ordering a test so that the Confidential Case Report forms can be completed accurately and efficiently once confirmed HIV test results are received from the laboratory.
- Anonymous testing sites, blood banks, plasma centers, and blinded and/or unlinked seroprevalence studies are exempt from HIV reporting.

Local Health Department HIV/AIDS Surveillance Programs: Interaction with Health Care Providers and Laboratories

Local health department HIV/AIDS Surveillance Programs will:

- a) Receive confirmed test reports from the laboratory.
- b) Match these records to the local HIV/AIDS Reporting System (HARS) data base.
- c) If the record matches another previously reported case, there is no follow-up and the case is not reported.
- d) If a match is found, the local health department will search for a Confidential Case Report form from the health care provider.
- e) If no Confidential Case Report form is found, the provider will be contacted for a completed form. (Local health department staff may provide direct assistance to health care providers to assist them in completing the Confidential Case Report form.)
- f) Once a completed Confidential Case Report form is received, the local health department is responsible for forwarding aggregate data to DHS/OA within 45 days.

Chapter

Laboratories: Step-by-Step HIV Reporting

The essential role of laboratories in California's HIV reporting system

Laboratories play a critical role in the reporting process. Although others are involved as well, it is the laboratory's report of a confirmed HIV test result that triggers HIV reporting.

When a laboratory receives a specimen from a health care provider for HIV testing *and* a test confirms the presence of HIV in that specimen, the laboratory becomes responsible for several reporting tasks, as shown in Figure 4.1. These are discussed below.

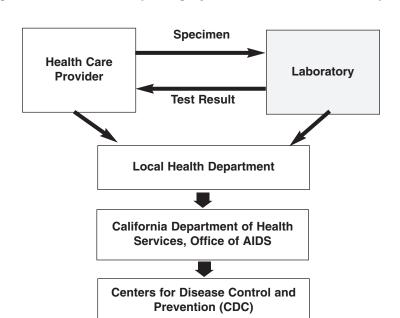


Figure 4.1: The Dual Reporting System for Non-Name HIV Reporting

Step 1: A Confirmed HIV Test

Laboratories are required to report the following tests:

- Tests verifying the presence of HIV infection, a component of HIV, or antibodies to or antigens of HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody tests; or
- All tests used to monitor HIV infection, including HIV nucleic acid detection (e.g., viral load).

Laboratories are **not** required to report findings for the following tests to the local health department:

- Enzyme-linked immunosorbent assay (ELISA) sometimes called enzyme immunoassay (EIA)
- CD4 or CD4/CD8 ratios
- Drug-resistance tests (genotypic/phenotypic tests)

Laboratories should **not** report tests on specimens from:

- anonymous testing sites
- blood banks
- plasma centers
- blinded and/or unlinked seroprevalence studies.

These are exempt from HIV reporting requirements.

Step 2: Creating a Soundex Code

In order to fulfill reporting requirements for all confirmed HIV test results, laboratories will need to generate a Soundex code of patients' last names. The code can be created either electronically (which is recommended) or manually. Both processes are described in Appendix E and in DHS form 8641 SC (9/01), which is also provided in Appendix E. (Form DHS 8641 SC (9/01) may be obtained from the DHS/OA website, www.dhs.ca.gov/AIDS).

A Soundex code converts last names into a code of one letter (the first letter of the last name) and three numbers that correspond to consonants in the last name. The Soundex code — together with complete date of birth, gender, and last four digits of a patient's Social Security Number — makes up the non-name code that will allow local health departments to unduplicate case reports. The laboratory that first receives a specimen for HIV testing is responsible for ensuring that a Soundex code is generated and reported to the requesting health care provider and local health department.

Soundex codes can be created electronically or manually. Generating a Soundex code electronically is preferable for several reasons:

- It is much easier, saving time and resources.
- It is more accurate because it is less prone to human error.
- Free, approved software is readily available for downloading from the DHS/OA website in numerous formats DOS, Windows, Access, Excel, SAS, Internet Explorer or Netscape, Adobe Acrobat, and MS Word. The website address is: www.dhs.ca.gov/aids. (Laboratories that cannot access these macros via the Internet may request a diskette version from their local health department.)

Step 3: Reporting Test Results to Health Care Providers and Local Health Departments

Within 7 calendar days of a confirmed HIV test, the laboratory must report results to the provider's local health department. The laboratory also reports results to the health care provider who ordered the test, although the time frame for this is not governed by the regulations.



If More Than One Laboratory Conducts Tests, Which One Reports?

The laboratory that *first receives the specimen* from a health care provider is responsible for reporting to the health care provider's local health department. This is true even if the specimen is forwarded to other laboratories (reference laboratories) for further testing.

Reporting to Health Care Providers

The specimen on which an HIV test is to be conducted should be accompanied by a laboratory requisition slip. The health care provider should have provided the laboratory with the following information for each specimen:

- the date the specimen was collected
- the patient's surname, gender, and date of birth
- the clinic/provider name, address, and telephone number.

If any of this information is missing, it is the laboratory's responsibility to contact the provider and request the missing information. The laboratory may proceed with testing the specimen, but should contact the health care provider to obtain the missing information before reporting confirmed HIV test results to the local health department.

Should the provider refuse to furnish the above information, the laboratory should report the confirmed test to the local health department with the information available. The local health department will follow up with the health care provider to obtain the missing information.

The laboratory that first received the specimen must report the following information to the health care provider for all confirmed HIV tests:

- The specimen number assigned by the laboratory (accession number)
- Confirmed test results
- Soundex code.

Types of laboratory's preprinted requisition slips

Table 4.1, below, shows the types of laboratory preprinted requisition slips that may be used by different types of providers and describes the laboratory-generated report numbers and reporting responsibilities associated with each. Samples of several completed laboratory preprinted requisition forms are found in Appendix C.

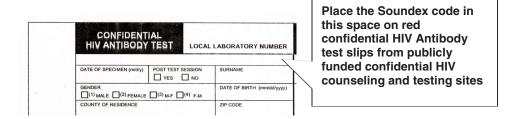
Table 4.1: Laboratory Preprinted Requisition Forms						
Form: Laboratory preprinted requisition forms		Red Confidential HIV Antibody Test form (DHS 8257C (1/02))	Purple Anonymous HIV Antibody Test form (DHS 8257A (1/02))			
Used by:	Health Care Providers, some publicly funded HIV counseling and test- ing (C&T) sites	Majority of publicly funded confidential HIV C&T sites	ATS, other anonymous publicly funded HIV C&T sites			
Specimen report number as assigned by the laboratory Unique specimen number assigned by the laboratory or other laboratory tory accession number		California DHS/OA 8-digit client ID number	California DHS/OA 8-digit client ID number			
Should a confirmed HIV test be reported to the health department? Yes, unless the specimen came from an exempted site		Yes	No			



Where should the laboratory record the Soundex code?

The current versions of laboratory reports to health care providers may not include a specific, labeled spot for entering the Soundex code. Laboratories should determine an appropriate empty space where the code will be entered. On the new red Confidential HIV Antibody Test slips (DHS 8257C (1/02)) used by publicly funded confidential counseling and testing sites, for example, enter the code in the empty space just above the patient's surname, as shown below.

Publicly Funded Confidential Test Sites



Reporting to Local Health Departments

Within 7 calendar days of a determining a confirmed HIV test result, laboratories must forward similar information to the provider's local health department. This can be accomplished using a paper form or via electronic reporting. Laboratories must contact local health departments before reporting electronically.

Paper Reporting

The DHS/OA has developed a standardized paper report form for laboratories that do not use electronic reporting (or for laboratories that report to local health departments that cannot receive the information in electronic format). A copy of this form is provided in Appendix F and may be used by laboratories as is, or they may develop their own form containing these elements.

The form, "Notification of Confirmed Human Immunodeficiency Virus (HIV) Test Result by Laboratory to Local Health Department, 06/2002," may be obtained from the DHS/OA website (www.dhs.ca.gov/AIDS). This form asks the laboratory to submit the following:

- Partial Non-Name code (Soundex, DOB, gender)
- Specimen report number as assigned by the laboratory (accession number or other unique specimen identifier)
- Test results

In addition, laboratories must report the following to local health departments:

- The date the specimen was tested
- The provider/clinic's name, address, and telephone number (from the laboratory slip)
- The laboratory's name, address, and telephone number.

Electronic Reporting

As with Soundex codes, the DHS/OA recommends electronic reporting of laboratory results to local health departments whenever possible – especially for those with a large volume of testing. Instructions for electronic reporting to local health departments are provided in Appendix F.

Special Considerations for Laboratories

Because the system is laboratory-driven, laboratories play an essential role in HIV nonname code reporting. Timely reporting of confirmed HIV test results – with a Soundex code that will be used to create a non-name code – allows local health departments to fulfill their responsibilities to create an unduplicated count of HIV cases.

Laboratories may encounter some unique jurisdictional issues as they attempt to meet the reporting requirements of the new regulations. For example, in some cases, individual laboratories may be one of several involved in the testing process. The laboratory that first received the specimen is the one responsible for reporting to the provider's local health department.

If a California laboratory receives a specimen from an out-of-state laboratory or provider, the confirmed HIV test results should be reported to the state health department of the state in which the specimen originated.

If a California laboratory receives a confirmed HIV test result from an out-of-state laboratory for a specimen that originated in California, the California laboratory should report the test results to the local health department of the provider who submitted the specimen.

Summary

Laboratories' specific HIV non-name code reporting responsibilities include:

- Report only confirmed HIV test results, as specified in the regulations.
- Generate a Soundex code (manually or electronically) for confirmed HIV test results, using the patient's surname. Forward the Soundex code along with the test results to the health care provider and local health department.
- Track down missing information from the provider and check on any discrepancies.
- Report within 7 calendar days of determining a confirmed HIV test to the local health department where the health care provider facility is located.

Local Health Department HIV/AIDS Surveillance Programs: Interaction with Health Care Providers and Laboratories

Local health department HIV/AIDS Surveillance Programs will:

- Receive confirmed test reports from the laboratory.
- Match these records to the local HIV/AIDS Reporting System (HARS) data base.
- If the record matches another previously reported case, there is no follow-up and the case is not reported.
- If a match is found, the local health department will search for a Confidential Case Report form from the health care provider.
- If no Confidential Case Report form is found, the provider will be contacted for a completed form. (Local health department staff may provide direct assistance to health care providers to assist them in completing the Confidential Case Report form.)
- Once a completed Confidential Case Report form is received, the local health department is responsible for forwarding aggregate data to DHS/OA within 45 days.

Chapter

Questions & Answers

Answers to common questions and concerns

FOR HEALTH CARE PROVIDERS

The following document is designed to provide a quick reference guide for California health care providers to assist them in understanding their roles and responsibilities for reporting HIV by Non-Name Code. For a copy of the complete HIV reporting regulations text, please refer to the Department of Health Services (DHS), Office of AIDS (OA) website at www.dhs.ca.gov/AIDS/ and Appendix A.

1. Please describe the HIV reporting process.

HIV (in the absence of an AIDS diagnosis) is now a reportable communicable disease in California. Cases are to be reported by a Non-Name Code instead of the patient's name. The process involves a dual reporting system wherein both the clinical laboratory and the health care provider report selected components of the Non-Name Code for the same case to the local health department (LHD) HIV/AIDS Surveillance Program. This process provides a built in checks-and-balances system for matching and unduplicating reported cases of HIV infection. For specific information about the HIV reporting process, please refer to the HIV reporting regulations text and the HIV Reporting Flow Chart which are available on the OA website and in Appendix B. The HIV reporting regulations are published in the California Code of Regulations, Title 17, Division 1, Chapter 4, Subchapter 1, Article 3.5, Sections 2641.5 - 2643.2.

2. How many days do providers have to report and to whom do they send the report?

According to Section 2643.5(c) of the HIV reporting regulations, health care providers must report "confirmed HIV test results" to the local health department within seven calendar days of receiving the confirmed test result and Partial Non-Name Code from the laboratory. Providers must report by completing the California Department of Health Services HIV/AIDS Confidential Case Report form DHS 8641A or DHS 8641P.

3. Are drug and alcohol programs, developmental centers, and state hospitals required to report?

Yes. All providers submitting HIV laboratory tests who can receive the test results, except those exempted in Section 2643.20 of the HIV reporting regulations, must report confirmed cases to the local health department.

4. What is the difference between the Non-Name Code and the Partial Non-Name Code?

The Non-Name Code (NNC) consists of the patient's Soundex (a four digit alphanumeric code that is derived from the patient's last name), date of birth, gender and last four digits of the patient's social security number. The Partial Non-Name Code consists of the first three elements of the NNC (Soundex, date of birth and gender). Laboratories are responsible for submitting the Partial Non-Name Code to the health care provider (HCP). The HCP completes the code by adding the last four digits of the social security number via completion of a California Department of Health Services, HIV/AIDS Confidential Case Report form. This form is submitted to the LHD HIV/AIDS Surveillance Program.

5. Where do providers obtain the HIV/AIDS Confidential Case Report form?

Copies of the case report forms may be obtained from your local health department's HIV/AIDS Surveillance Program.

6. When completing the HIV Confidential Case Report form, what is the determining factor in identifying whether a patient's gender is "3" or "4"?

There are four genders identified on the California Department of Health Services, Adult HIV/AIDS Confidential Case Report form: 1-male; 2-female; 3-transgendered male to female; and 4-transgendered female to male. The gender selected should be how the patient self-identifies.

7. The lab data on the case report form asks for "detectable" viral load results. Are "undetectable" viral load results reportable?

Yes. "Undetectable" viral loads are reportable. The FDA has approved viral load testing only as a method to monitor the efficacy of HIV treatment, therefore it is to be assumed that these tests are being ordered on patients who are infected. If viral load tests are ordered for persons whose sero-status is unknown (to determine recent exposure for example), it will be incumbent upon physicians and public health staff to resolve which tests are subject to HIV reporting regulations. Since HCPs only submit one case report per patient, reporting undetectable viral loads should not impose an undue burden on the HCP.

8. Should a provider keep a copy of the HIV case report form in the patient's medical records?

This is not a requirement and is the decision of the provider. It may help substantiate the reporting of a case and assist in case follow-up.

9. Do the HIV reporting regulations require that a health care provider keep a cross referencing system on who they report?

Yes. Section 2643.5(h) of the HIV reporting regulations states, "... the health care provider shall maintain a system which cross-references patient data by using either the Partial Non-Name Code or the Non-Name Code. This system shall be used only to exchange information with the Local Health Officer in order to complete or unduplicate the HIV case reports." LHD HIV/AIDS Surveillance Programs can supply providers with a sample cross referencing form that can be copied in its entirety or modified to meet a provider's specific record-keeping system.

10. Are health care providers "legally" required to inform the patient about HIV reporting when ordering a HIV test?

No. There are no laws or regulations that require providers to inform or educate their patients that confirmed cases of HIV are reported by Non-Name Code. Some providers may feel they have an ethical obligation to inform their patients, while others may choose not to inform patients of HIV or any other communicable disease reporting requirements.

11. What if the patient requests anonymous testing?

Anonymous testing is available in most local health departments.

12. Are physicians who offer anonymous testing required to report confirmed positive HIV cases?

If a physician knows the patient's identity and/or records the positive test result in the patient's medical record, then the test is not anonymous and the physician is required to report the case. However, if a physician offers truly anonymous HIV testing, then confirmed test results are exempt from reporting. It is important to note that HIV positive persons who seek medical care after testing in an anonymous clinic or physician's office will be reported at time of treatment (because anonymity is relinquished).

13. How is confidentiality assured for HIV reporting?

Individuals are protected by California law that prohibits unauthorized disclosure of any information about an individual who takes an HIV test. With non-name code reporting, these protections go beyond those that govern AIDS reporting, since the code cannot be traced back to a person's name.

14. What if the patient is under 13?

For patients who are under the age of 13, health care providers will complete the Pediatric HIV/AIDS Confidential Case Report.

15. How can I produce the Soundex myself?

You may go to the OA website (www.dhs.ca.gov/AIDS) to download the OA-approved Soundexing programs or contact your local health department to obtain a copy on diskette. The programs are in DOS, Windows, Access, Excel, SAS, and JavaScript. Any other Soundexing programs available on the Internet or elsewhere are not authorized for HIV reporting procedures.

16. Are there actual Social Security Numbers that end in four zeroes?

No. The last four digits of the Social Security Number are issued in a sequential numbering order. After a sequence reaches "9999," the next sequence starts over at "0001."

17. Is electronic reporting for providers available?

No. Regular mail is the only acceptable method of transferring data. Consistent with AIDS case reporting, transmission by e-mail and fax must be avoided. Contact your local health department HIV/AIDS Surveillance Program to arrange to transfer data by diskette.

18. Are there legal ramifications for health care providers who fail to report confirmed HIV cases?

Yes. Every person charged with a duty under the HIV Reporting Regulations who willfully neglects or refuses to report in accordance with the regulations is guilty of a misdemeanor under Health and Safety Code section 100182 and may be subject to prosecution.

19. Who will provide HIV Non-Name Code Reporting training and technical assistance for laboratories and health care providers?

The DHS/OA has contracted with ETR Associates to provide training for laboratories and health care providers across the state. In addition, local health departments are resources for laboratories and health care providers who have questions about reporting procedures.

20. What if I need forms and/or more information?

Contact your local health department (see Appendix C for a contact list) or the DHS/OA: www.dhs.ca.gov/AIDS or 916-445-0553. For information specific to HIV Non-Name Code Reporting training events, contact ETR Associates (www.etr.org, or 831-438-4060).

Chapter

Conclusion

A smooth transition to an efficient HIV non-name code reporting system will require cooperation among health care providers, laboratories, and public health agencies at the local, state, and federal levels. With the input of representatives from each of these groups, the DHS has designed a system that provides unduplicated counts of HIV cases, protects patient confidentiality, and builds on existing disease reporting protocols.

This manual and the training that accompanies it are in place to answer questions, anticipate and resolve problems before they occur, and offer resources for answering new questions as they arise.

With your help, the transition period can be short as well as smooth. Thank you for your current and future contributions to helping California monitor both HIV and AIDS, so that prevention and treatment efforts can reach those most in need.

All of California looks forward to the day when all surveillance systems will document a decline in HIV/AIDS in California, our country, and around the globe.



Comments? Ideas? Suggestions?

Please share your insights and comments with us so that we may improve future training and materials. Send your comments to our training contractor, ETR Associates (christinaa@etr.org), or to the DHS/OA (www.dhs.ca.gov/AIDS or 916-445-0553

Other comments should be directed to Jim Creeger, Chief, HIV/AIDS Case Registry, California Department of Health Services at jcreeger@dhs.ca.gov.

APPENDIX A: REGULATIONS

Article 3.5 Reporting of Human Immunodeficiency Virus (HIV) Infection Sub-Article 1. Definitions

(1) Adopt Section 2641.5 as follows:

Section 2641.5 Alternative Testing Site.

"Alternative Testing Site" means an anonymous HIV testing site funded by the California Department of Health Services, administered by a county health department and operated pursuant to Health and Safety Code, Sections 120890-120895.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(2) Adopt Section 2641.10 as follows:

Section 2641.10. Anonymous Counseling and Testing Program.

"Anonymous Counseling and Testing Program" means a program offering HIV counseling and testing while maintaining anonymity of the patient.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(3) Adopt Section 2641.15. as follows:

Section 2641.15. Anonymous HIV Test.

"Anonymous HIV Test" means an HIV test that maintains the anonymity of the patient.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

(4) Adopt Section 2641.20 as follows:

Section 2641.20. Biological Specimen.

"Biological specimen" means any material that is derived from the human body.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Section 1206, Business and Professions Code; Sections 100180, 101160, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(5) Adopt Section 2641.25 as follows:

Section 2641.25. Confidential HIV Test.

"Confidential HIV Test" means an HIV test that links the test results to the patient in a restricted manner to protect against unauthorized disclosure of the identity of the patient.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775 and 121025, Health and Safety Code.

(6) Adopt Section 2641.30 as follows:

Section 2641.30. Confirmed HIV Test.

"Confirmed HIV test" means: (a) a procedure which verifies the presence of HIV infection as determined by any clinical laboratory test or examination used to detect the presence of HIV, a component of HIV, or antibodies to or antigens of HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody tests; or (b) for the purpose of this Article, all tests used to monitor HIV infection, including HIV nucleic acid detection.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 1206, 1206.5, 1241, 1265 and 1281, Business and Professions Code; Sections 100180, 101150, 101160, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(7) Adopt Section 2641.35 as follows:

Section 2641.35. Department.

"Department" means the California Department of Health Services, Office of AIDS. Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(8) Adopt Section 2641.45 as follows:

Section 2641.45. Health Care Provider.

"Health care provider" means an individual who submits a biological specimen to a laboratory for a test to detect the presence of HIV, a component of HIV or antibodies to or antigens of HIV, receives the test results and is; (a) licensed under the provisions of Business and Professions Code, Division 2 (Healing Arts) and acting within his or her scope of practice, or; (b) a designee of a physician and surgeon acting under the general supervision of that physician or surgeon, or; (c) a person working in a publicly-funded confidential counseling and testing program acting under the general supervision of, and following the protocols approved by, the local Health Officer for the local health department.

Authority cited: Sections 100180, 100275, 101160, 120125 and 120130, Health and Safety Code.

Reference: Sections 1206, 1206.5, 1241, 1281 and 1285, Business and Professions Code; Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(9) Adopt Section 2641.50 as follows:

Section 2641.50. Health Officer and Local Health Officer.

"Health Officer and Local Health Officer" means the officer appointed by the local governing body (county, city, and district), as defined in Section 2500.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

(10) Adopt Section 2641.55 as follows:

Section 2641.55. HIV/AIDS Case Report.

"HIV/AIDS Case Report" means California Department of Health Services HIV/AIDS Confidential Case Report form, Adult (DHS 8641A (9/01) or Pediatric (DHS 8641P (9/01), hereby incorporated by reference in this Article and available from the local health department or the Department.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(11) Adopt Section 2641.60 as follows:

Section 2641.60. Laboratory.

"Laboratory" means a 'clinical laboratory,' a 'physician office laboratory,' or a 'public health laboratory,' as defined in Business and Professions Code, Section 1206, that is authorized to perform clinical laboratory tests or examinations in California, or a clinical laboratory located outside of the State of California that is licensed pursuant to business and Professions Code Section 1241(a) and that tests specimens originating in California.

Authority cited: Sections 1224 and 1288, Business and Professions Code; Sections 100180, 100275, 101160, 120125 and 120130, Health and Safety Code.

Reference: Sections 1206, 1241, 1220, 1265 and 1281, Business and Professions Code.

(12) Adopt Section 2641.65 as follows:

Section 2641.65. Laboratory Test.

"Laboratory test" means a clinical laboratory test or examination as defined in Business and Professions Code, Section 1206 (a) (4) and performed by a laboratory as defined in this Article.

Authority: Sections 1224 and 1288, Business and Professions Code; Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 1202.5 and 1206, Business and Professions Code; Section 101160, Health and Safety Code.

(13) Adopt Section 2641.70 as follows:

Section 2641.70. Local Health Department.

"Local health department" means the governing body providing public health services to cities and/or counties, as identified in Health and Safety Code, Section 101185.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(14) Adopt Section 2641.75 as follows:

Section 2641.75. Non-Name Code.

"Non-Name Code" means a designation required by Section 2643.5 of this Article, that does not readily identify an HIV-infected individual. Components of the Non-Name Code shall be listed in the following order, and shall consist of an individual's:

- (a) Soundex code;
- (b) complete date of birth (2-digit month, 2-digit day, 4-digit year);
- (c) gender (male [1], female [2], transgender male-to-female [3], or transgender

female-to-male [4]); and

(d) last four digits of the Social Security Number (if not available, use four digits of

zero).

Authority cited: Sections 100180, 100275, 120125, 120130 and 120140, Health and Safety Code.

(15) Adopt Section 2641.77 as follows

Section 2641.77 Partial Non-Name Code

A Partial Non-Name Code means a designation required by Section 2643.10 of this Article, that does not readily identify the HIV-infected individual. Components of the Partial Non-Name Code shall be listed in the following order, and shall consist of an individual's:

- (a) Soundex code;
- (b) complete date of birth (2-digit month, 2-digit day, 4-digit year) and;
- (c) gender (male [1], female [2], transgender male-to-female [3], or transgender

female-to-male [4]).

Authority cited: Sections 100180, 100275, 120125, 120130 and 120140 Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(16) Adopt Section 2641.80 as follows:

Section 2641.80. Personal Information.

"Personal information" means an individual's complete Social Security Number, complete name or surname, home address, California driver's license or identification number, electronic mail address or telephone number.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

(17) Adopt Section 2641.85 as follows:

Section 2641.85. Publicly-Funded Confidential Counseling and Testing Program. "Publicly-funded Confidential Counseling and Testing Program" means a program financed by federal, state or local governmental agencies that provides confidential HIV tests to patients.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(18) Adopt Section 2641.90 as follows:

Section 2641.90. Soundex Code.

"Soundex code" means a phonetic, alphanumerical formula which is used to convert the first letter and sequential consonants of an individual's surname into an algorithm. The Soundex code instructions are identified by the Department as form DHS 8641 SC (9/01), hereby incorporated by reference in this Article.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Healthand Safety Code.

Sub-Article 4. Reporting Requirements

(19) Adopt Section 2643.5 as follows:

Section 2643.5. HIV Reporting by Health Care Providers.

- (a) Each health care provider that orders a laboratory test used to identify HIV, a component of HIV, or antibodies to or antigens of HIV shall submit the following to the laboratory performing the test:
 - (1) A pre-printed laboratory requisition form which includes all documentation as specified in 42 CFR 493.1105 (57 FR 7162, Feb. 28, 1992, as amended at 58 FR 5229, Jan. 19, 1993) and adopted in Business and Professions Code, Section 1220, or;
 - (2) A completed Department of Health Services Counseling and Testing Program Confidential HIV Antibody Test laboratory requisition form, DHS 8257C (1/02), hereby incorporated by reference in this Article.

- (b) The person authorized to order the laboratory test shall include the following when submitting information to the laboratory:
 - (1) Patient surname; and
 - (2) Patient date of birth (2-digit month, 2-digit day, 4-digit year); and
 - (3) Patient gender (male, female, transgender male-to-female, or transgender female-to-male); and
 - (4) Date biological specimen was collected; and
 - (5) Name, address, telephone number of the health care provider and the facility where services were rendered, if different.
- (c) Each health care provider shall, within seven calendar days of receipt of a patient's confirmed HIV test and Partial Non-Name Code from a laboratory, complete the Non-Name Code (as specified in Section 2641.75) and report the confirmed HIV test to the local Health Officer for the jurisdiction where the health care provider facility is located. The report shall consist of a completed copy of the HIV/AIDS Case Report form.
- (d) HIV reporting by Non-Name Code to the local Health Officer, via submission of the HIV/AIDS Case Report, shall not supplant the reporting requirements in Article 1 of this Subchapter when a patient's medical condition progresses from HIV infection to an Acquired Immunodeficiency Syndrome (AIDS) diagnosis.
- (e) When reporting a confirmed HIV test, a health care provider shall not report a patient's personal information to the local Health Officer except for patients whose clinical conditions meet the AIDS reporting criteria, as specified in Article 1 of this Subchapter.
- (f) A health care provider who receives notification from an out-of-state laboratory of a confirmed HIV test for a California patient shall report the findings to the local Health Officer for the jurisdiction where the health care provider facility is located.
- (g) When a health care provider orders multiple HIV-related viral load tests for a patient, or receives multiple laboratory reports of a confirmed HIV test, the health care provider shall be required to submit only one HIV/AIDS Case Report, per patient, to the local Health Officer.
- (h) For all HIV-infected patients without an AIDS diagnosis, the health care provider shall maintain a system which cross-references patient data by using either the Partial Non-Name Code or the Non-Name Code. This system shall be used only to exchange information with the Local Health

Officer in order to complete or unduplicate the HIV case reports.

(i) Information reported pursuant to this Article is acquired in confidence and shall not be disclosed by the health care provider except as authorized by this Article, other state or federal law, or with the written consent of the individual to whom the information pertains or the legal representative of that individual.

Authority cited: Sections 100180, 100275, 120125, 120130 and 120140, Health and Safety Code.

Reference: Sections 1202.5, 1206, 1206.5, 1220, 1241, 1265 and 1281, Business and Professions Code; Sections 100180, 101160, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(20) Adopt Section 2643.10 as follows:

Section 2643.10. HIV Reporting by Laboratories.

- (a) The laboratory director or authorized designee shall create a Partial Non-Name Code (as specified in Section 2641.77) for each confirmed HIV test.
- (b) The laboratory director or authorized designee shall, within seven calendar days of determining a confirmed HIV test, report the confirmed HIV test to the Health Officer of the local health jurisdiction where the health care provider facility is located. The report shall include the:
 - (1) Partial Non-Name Code of the patient; and
 - (2) Name, address, and telephone number of the health care provider and the
 - facility that submitted the biological specimen to the laboratory, if different.; and
 - (3) Name, address, and telephone number of the laboratory; and
 - (4) Laboratory report number as assigned by the laboratory; and
 - (4) Laboratory results of the test performed; and
 - (5) Date the biological specimen was tested in the laboratory.
- (c) A laboratory shall not transmit a patient's personal information to the local health department.
- (d) A laboratory that receives incomplete patient data from a health care provider for a biological specimen with a confirmed HIV test, shall contact the submitting health care provider to obtain the information required pur-

suant to Section 2643.5 (b) (1)-(5), prior to reporting the confirmed HIV test to the local Health Officer.

- (e) A laboratory shall convey the patient's Partial Non-Name Code to the submitting health care provider when reporting confirmed HIV test results.
- (f) If a laboratory transfers a biological specimen to another laboratory for testing, the laboratory that first receives the biological specimen from the health care provider shall report confirmed HIV tests to the local Health Officer.
- (g) Laboratories shall not submit reports to the local health department for confirmed HIV tests for patients of an Alternative Testing Site or other anonymous HIV testing program, a blood bank, a plasma center, or for participants of a blinded and/or unlinked seroprevalence study.
- (h) When a California laboratory receives a biological specimen for testing from an out-of-state laboratory or health care provider, the California director of the laboratory shall ensure that a confirmed HIV test is reported to the state health department in the state where the biological specimen originated.
- (i) When a California laboratory receives a report from an out of state laboratory that indicates evidence of a confirmed HIV test for a California patient, the California laboratory shall notify the local Health Officer and health care provider in the same manner as if the findings had been made by the California laboratory.
- (j) Information reported pursuant to this Article is acquired in confidence and shall not be disclosed by the laboratory except as authorized by this Article, other state or federal law, or with the written consent of the individual to whom the information pertains or the legal representative of the individual.

Authority cited: Sections 1224, Business and Professions Code; Sections 100180, 100275, 120125, 120130 and 120140, Health and Safety Code.

Reference: Sections 1206, 1206.5, 1209, 1220, 1241, 1265, 1281 and 1288, Business and Professions Code; Sections 100180, 101150, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(21) Adopt Section 2643.15 as follows:

Section 2643.15 HIV Reporting by Local Health Officers.

- (a) The local Health Officer or his or her authorized designee shall match and unduplicate laboratory reports of confirmed HIV tests with the local health department HIV/AIDS registry database and with HIV/AIDS Case Reports received from health care providers and not entered into the database.
- (b) The Health Officer or his or her authorized designee shall, within 45 calendar days of receipt of a laboratory report of a confirmed HIV test, submit unduplicated HIV/AIDS Case Reports to the Department.
 - (1) HIV/AIDS Case Reports shall be sent by courier service, U.S. Postal Service Express or Registered mail, or other traceable mail to the California Department of Health Services, Office of AIDS, HIV/AIDS Case Registry.
 - (2) The local Health Officer or his or her authorized designee shall not report confirmed HIV tests for patients of an Alternative Testing Site or other anonymous counseling and testing program, a blood bank, a plasma center, or for participants of a blinded and/or unlinked HIV seroprevalence study.
- (c) The local Health Officer or his or her authorized designee shall not submit an HIV/AIDS Case Report to the Department for an infant under the age of 18 months, unless the infant's HIV infection is confirmed.
- (d) Information reported pursuant to this Article is acquired in confidence and shall not be disclosed by the local Health Officer or his or her authorized designee except as authorized by this Article, other state or federal law, or with the written consent of the individual to whom the information pertains or the legal representative of the individual.

Authority cited: Sections 100180, 100275, 120125, 120130 and 120140, Health and Safety Code.

Reference: Sections 100180, 120175, 120775, 120885-120895 and 121025, Health and Safety Code.

(22) Adopt Section 2643.20 as follows:

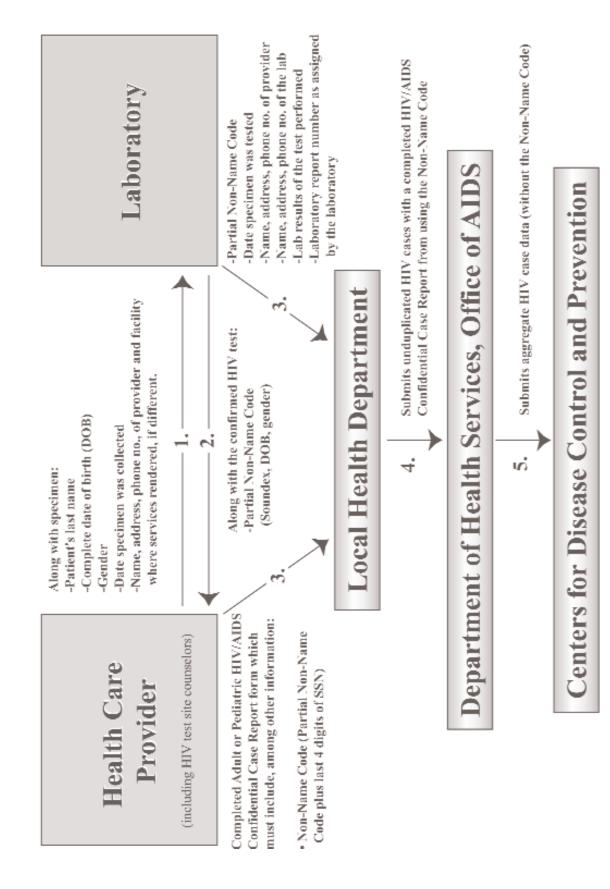
Section 2643.20. HIV Reporting Exemptions.

Alternative Testing Sites; other anonymous or unlinked HIV testing programs; blood banks; plasma centers; and blinded and/or unlinked sero-prevalence studies are exempt from these HIV reporting regulations.

Authority cited: Sections 100180, 100275, 120125 and 120130, Health and Safety Code.

APPENDIX B: FLOWCHART

CALIFORNIA'S NON-NAME BASED HIV REPORTING PROCESS



Source: California Department of Health Services, Office of AIDS

APPENDIX C: Samples of Completed Forms

- Laboratory Preprinted Requisition Form
- Publicly-funded Confidential HIV Antibody Test Forms (Requisition and Result form)
- Adult HIV Confidential Case Report Form
- Pediatric HIV Confidential Case Report Form
- Report Form for HIV-1

-SAMPLE-Requisition sent from Health Care Provider to the Laboratory

DOB: 05/25/76	76	LAB	LABORATORY REQUISITION	NO	Gender: Male
Patient Name:	John Smith	Patient /	Patient Account Number:		Chart #: S9092
Provider: Sam Getwell, MD	Setwell, MD	Provider #: 34297	297 D.O.S: 09/18/02		Insurance: Pacificaning
Provider address:	Provider address: 456 Center St., Anytown, USA 90000	nytown, USA 9		Provider telephone #:	1-800-555-2222
PRIORITY: J ST	PRIORITY: STAT ASAP ROUTINE	E PATIENT PRP: J	PRP: J FASTING M NON-FASTING	ON-FASTING	TELEPHONE J FAX
DX1:	DX3:	IF 800 OR 900 SERIES DX NEED A DOI OR ONSET:	×	ADVANCE NOTICE TO BENEFICIARY DONE:	COPY OF RESULTS TO:
	Hours Fasting:	Hours Post PP:		Hours Post Med:	
	Collection By:	Date/Time	Pre-Op Surg Date:	ate: SMSC	□ DSCH
	TEST ORI	DER AND INTERPF	TEST ORDER AND INTERPRETATION CONSULT AVAILABLE UPON REQUEST	ABLE UPON REQUES	T
□ 85002	Bleeding Time	□ 85021	Hemogram	86038	ANA
☐ 85025	CBC (auto diff)	⊒ 83020	Hgb Electophoresis		ASO
□ 85023	CBC (man diff)	□ 85730	PTT	□ 86156	Cold Agglutinin
□ 82728*	Ferritin	☐ 85595	Platelet, auto	© 86703	HIV ab
□ 85384	Fibrinogen	☐ 85610	Protime	80298	Mono Spot
□ 85014	Hematocrit	□ 85045	Rectic Count	₩ 86592*	RPR
□ 85018	Hemoglobin	☐ 85651	Sed Rate	Ø	Western Blot
					sanjahina X∩-*

Local Laboratory 123 Main St • Anytown USA 90000 1-800-555-1111

-SAMPLE-Requisition sent to Laboratory from Publicly Funded Confidential Test Site

23901 ATTACH LABEL TO REPORT FORM AND BLOOD SPECIMEN			\d0 - \d0 - \d0 - \d0	S P P P P P P P P P P P P P P P P P P P	F-72#,	_		- LD-1,457-3		SEND REMAINING LABELS WITH COPIES 1 & 2 OF FORM TO THE	
CLIENT ID# F2 -1.857-3 CALIFORNIA STATE DEPARTMENT OF HEALTH SERVICES	LABORATORY USE ONLY	ELISA: SEACTIVE NON-REACTIVE	SUPPLEMENTAL TEST PEFFORMED:	BEACTIVE BEACTIVE	. —	SUMMARY INTERPRETATION:	☐ NO HIV ANTIЗODY DETECTED ☐ NO HIV ANTIЗODY DETECTED	INCONCLUSIVE-SU3MIT ANOTHER SPECIMEN SEE ENCLOSED NOTE	NCTE:	CATE RECEIVED 3Y LAB CATE REFORTED	
CONFIDENTIAL HIV ANTIBODY TEST LOCAL LABORATORY NUMBER		DATE OF SPECIMEN 1950/ POST TEST SESSION SURNAME SMITH SINCT $\frac{9720/02}{1000}$	DATE OF BIRTH (mm/34kyyyy) FM $05/25/1976$	COUNTY OF RESIDENCE ANY COUNTY ZIP CODE 9000	PPEVIOUS HIV ANTIBODY TEST? \uprightarrow YES \uprightarrow IF YES, WH \uprightarrow NG \uprightarrow V	S∃ATIVE ☐ UNKNOWN	LABOPATORYNAME & ADDRESS LOCAL LABORATORY	Anytown, USA 90000	CUNICSTENMME, ADDRESS & PHONE: LOCAL Health Care Provider 4-26 Center St	Anytown, USA 90000	RETURN ARRON THAN TO DATE (prindd 1999) 09/30/2002

-SAMPLE-Result sent back to Publicly Funded Confidential Test Site from the Laboratory

23901 I ATACH LABEL TO REPORT FORM AND BLOOD SPECIMEN			P4 - PGU-1657-3	F PSD-1857-3	C_C_L_L_L_L_L_L		☐ L20-1857-3			(20		COPIES 1 & 2 OF FORM TO THE	E LABORATORIES.
CLIENT ID# L20-1.857-3 CALFORNIA STATE DEPARTMENT OF HEALTH SERVICES	LABORATORY USE ONLY	ELISA: X REACTIVE	SUPPLEMENTAL TEST PERFORMED: FA Marstran and the party of the par	REACTIVE X REACTIVE	INDETERMINATE RY		M HIV AN IIBODY DETECTED NO HIV ANTIGODY DETECTED	☐ IN JON JULSIVE-SUBMIT ANOTHER SPECIMEN ☐ SEE EN JUSED NOTE	NOTE:			DATEREPORTED	4/54/05 10/03/05
85641972 Local Laboratory number		SCHNAME Smith		ZIP CODE 90000	UN <nown d#<="" fyes.="" th=""><th>NEGATVE UNKNOWN</th><th>Laboratory</th><th>Maint St /</th><th>Local Health Care Provider</th><th>426 Center St</th><th></th><th>1-800-555-2222</th><th>09/30/2002</th></nown>	NEGATVE UNKNOWN	Laboratory	Maint St /	Local Health Care Provider	426 Center St		1-800-555-2222	09/30/2002
CONFIDENTIAL HIV ANTIBODY TEST	Soundex Code: S530	$\frac{\text{DATE OF SPECIMEN}_{\text{off-y}}}{9720702} \frac{\text{POST TEST SESSION}}{\Box \text{VES}} $	GENDER GENDER (4) F-M	SOLNIY OF RESIDENCE ANY COUNTY	PREVIOUS HIV ANTIBODY TEST? X YES IND	"	<u> </u>	123 Maint	CLINIC/SITE NAVE, ADDRESS & PHONE: LOCA	426	Ant	10/8-1	RETURN APPOINTMENT DATE (IT TUCC/3939) $09/3$

State of California—Health and Human Services Agency

-SAMPLE-

Department of Health Services Office of AIDS HIV/AIDS Survellance Program

ADULT HIV/AIDS CONFIDENTIAL CASE REPORT (Patients ≥ 13 years of age at time of diagnosis)

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Check if HIV in	nfection is presur	ned to have	been acqu	ired outside U	nited SI	tates and	Territories.	Specify	country:					
Residence at diagr	nosis: City	our cit	Υ	Count	y you	ır hea	alth juriso	diction	State/Cour	ntry CA/(JSA	ZJI, co	ode 9X	XXX
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30 Correctional Fa	•												×	9
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"Type 11=NASBA (O	Drganon); 12=RT-PCK ;		/\ (Chiron); 18=				он4 ре	rcent				% [<u> </u>
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VII. FOR AIDS		VLY—Pat	ient-ide	ntifier info	rmati	on is n	ot transm				<u></u>	<u></u>		
Patient's name (last, fi	first, MI)							Telephane r	number)	s	ocial Security	Number		
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DHS 8641 A (9/01)				l					Λ	DULT HIVAIDS	CONFIDENTI	AL CASE REI	PORT-P	Page 1 of 2

VIII. C Inical Status										
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AIDS INDICATOR DISEASES		Def.	Pres.	Month	Year	AIDS INDICATOR DISEASES	Def.	Pres.	Month	Year
Candidiasis, bronchi, trachea, or lungs		1	NΛ			Lymphoma, Burkjtt's (or equivalent lerm)	1	NΛ		
Candidiasis, esophageal		1	2			Lymphoma. immunoblastic (or equivalent term)	1	NA		
Carcinoma, invasive cervical		1	NA			Lymphoma, primary in brain	1	NA		
Coccidioidomycosis, disseminated or extrapulmi	onary	1	NΛ			Mycobacterium avium complex or M.kansasii, disseminated or extrapulmonary	1	2		
Cryptococcosis, extrapulmonary Cryptosporidiosis, chronic intestinal		1	NΛ			M. tuberculosis, pulmonary	1	2		
(>1 month duration)		1	NA			M. tuberculosis, disseminated or extrapulmonary*	1	2		
Cytomegalovirus disease (other than in liver, spi or nodes)	een,	1	NΛ			Mycobacterium of other species or unidentified	1 .			
Cylomegalovirus relinitis (with loss of vision)		1	2			species, disseminated or extrapulmonary	1	2		
HIV encephalopathy		1	NΛ			Pneumocystis carinii pneumonia	1	2		
Herpes simplex: chronic ulcer(s) (>1 month dur	ation);					Pneumonia, recurrent, in 12-month period	1	2		
or bronchitis. pneumonitis, or esophagitis		1	NA NA			Progressive multifocal leukoencephalopathy	1	NA		
Histoplasmosis, disseminated or extrapulmonary Isosporiasis, chronic intestinal (>1 month duration)		1	NA NA			Salmone la septicemia, recurrent	1	NV		-
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IX. Treatment/Services Referrals	does this pe	adont n	ave an ii	minumou	CHOICH	y that would disquality himbries from the 7420 case definiti			<u> </u>	
IX. Treatment der viere Referrale			Yes	Na Uni	known	This patient has been enrolled at:				
Has the patient been informed of his/her HIV inf	ection?		Ж		9	Clinical Trial Clinic				
This patient's partner(s) has been or will be noting	fjed					1 NIH-sponsored 1 HRSA-sponsored				
about their HIV exposure and counseled by: The alth Department Physician/Providence Physician Providence Physician Providence Physician Physician	Mad n	atient	اراها	nknown		2 Other 2 Other				
This patient received or is receiving:	91 <u>(</u>	alieni			known	None None				
^ntiretroviral therapy					9	9 Unknown				
PCP prophylaxis			1	0	9	This patient's medical treatment is primarily reimbursed	-			
This patient is receiving or has been referred for		Yes		NA Uni			rivate insu			
HIV-related medical services Substance abuse treatment services			0		9		ther public nknown	e tunain	9	
								Yc	s No U	nknown
For women: ' This patient is receiving or has	been referr	red for	gynecolo	gical or	obstetr	ical services				9
										9
' This patient has delivered live (If yes and if delivered after 19						most recent hirth)		1	0	9
Child's date of birth Hospital of						Child's Soundex Child's state	patient ni	ımber		
Month Day Year							· ———			
City						State Line Line Line Line Line Line Line Lin				
X. Comments										
<u> </u>										
Persons with HIV infection without an AID with name. For additional information about	-					at name. Persons with conditions meeting AIDS ca call your local health department.	ise criter	ia mus	st be re	ported
XI. Provider Information										
Physician's name (last, first, MI) Getwell, Sam MD	Telephone		5-00		atient's m	necical record number Person completing form Tane Smith	nodceleT	e numbe	55-0	 0000
Address (rium ber. street) Your address	1(800	<u>/33</u>	<u></u>	Ci	ity	your city	SaleCA	ZIP	code 9XX	
1						<i>I</i>			1/ 1/	, , , ,

MAIL COMPLETED FORM TO YOUR LOCAL HEALTH DEPARTMENT.

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ADULT HIV/AIDS CONFIDENTIAL CASE REPORT—Page 2 of 2

State of California—Health and Human Services Agency

-SAMPLE-

Department of Health Services Office of AIDS HIV/AIDS Surveillance Program

PEDIATRIC HIV/AIDS CONFIDENTIAL CASE REPORT

(Patient	ts < 13 y	ears of ag	je at ti	ime o	of dia	gnos	sis.)							
Date form completed Report			I. He	ealth l	Depa	rtmen	t Use C	nly						
Month Day Year When Report Report	orting health (department Sta	ate patic	ու ոստե	oer			Ci	ty/county	pation	t numbo	or		
Month Day Year														
II. For HIV and AIDS Cases		For Non-A	AIDS C	ases	Only	,								
	nder	Last four digi	its of SSI	N Lab i	report i	number			*Conf	idential	C&T nu	ımber		
15 6 3 0 1110 2 11 6 11 9 9 71 1 5] Malə] Female	22	9 5	3	1 2	2. 2.	3 4 5	5 6	Putilish	need confid	lonilal source	line and lost	lan sites o	nlv
III. Demographic Information		ı											-	
Diagnosis status at report Age at Diagnosis Current status Diagnosis	ate of death Month Day	y Year	. ⊨			of Di	iagnosi	s						
3 Perinatally HIV exposed				Facility n	ame	Цел	lthy F ur city VUSA	amili	ا عوا	linic				
	tate/Territory	of death				1 1001	iny i	arriiii	رب ربا	11 110				
5 AIDS 9 Unknown	tato, ronnory	ui (icaiii	'	City		YOL	ur city	/						
6 Sercreverter				Chata (Ca	maken r									
Date of last medical evaluation Date of initial eva	luation for H	V infection		State/Co	Untry	CA	1/USA	l						
Month Day Year Month Day	Year													
				Facility	tvne (c	check or	16)							
Was reason for initial HIV evaluation due to clinical signs and syl X yes value to value to clinical signs and syl	mptoms?			01 Phy:	sician,	HMO	Center							
Race/ethnicity						al Facilit								
1 White (non-Hispanic)	3 Hisp			_		patient	•							
4 Asian/Pacific Islander 5 American Indian/Alaska Native Country of birth	e [9]Not	specified				utpatien								
✓ U.S. Territories (including Puerto Ri∞)	9 Unki	nown	ľ	88 Othe	er (spe	clty):								
8 Other (specify):				 99 Unk	nown									
Check if HIV infection is presumed to have been acquired outs	side United St	ates and Territo	ories.											
Specify country:				Facility XI Pub	-	check) ו			∏		ها			
Residence al diagnosis.				Z] Pub	IIC	كا	Private	L	Federa	il.	9 Un	known		
your city your county State County CA	y /USA	ZIP code 9000	00											
V. Patient/Maternal History (Respond to all ca	tegorles.)	ı												
Child's biologic mother's HIV infection status: (check one)														
1 Refused HIV testing	2 Kno	wn to be <i>un</i> infe	ected afte	er this c	hlld's t	oirth	X HI∕	/ status	unknaw	m				
Diagnosed with HIV intection/AIDS:	_						_							
Before this child's pregnancy		ne of delivery					=		child's bir					
During this child's pregnancy	Befo	ro c hild's birth,	, exact p	cried ur	iknowr	1	LO I III	/-infect	od, unkn	own wh	nen diag	Inosed		
Date of <i>mother's</i> first positive HIV confirmatory test:	Year	Mother was c	ounseled	d about	HIV te	sting du	ring this p	regnan	ıcy, labor	r, or del	livery [lo Ur	known
After 1977, this child's biologic mother had:	Yes N	o Unknown B	Before th	ne diagi	nosis d	of HIV i	nfection//	AIDS. t	his <i>chil</i> d	had:		Yes I	No Un	known
Injected nonprescription drugs	X c	9			-		emophilia/	-		order	[1 >	《	3
HETEROSEXUAL relations with:	Yes N	o Unknown	-				or VIII (He							
Intravenous/injection drug user	X 0		_	tor IX (F			ाध्य /blood co	her (sp				Van 1	مل ما	
Bisexuai maje	-							•			[1 2eY	K On	g
Male with hemophilia/coagulation disorder			•	1cnth	Year	¬		Month		٦	[`	
Transfusion recipient with documented HIV infection			First:			J	Last:				_	Yes I	No Un	known
Transplant recipient with documented HIV infection					•		organs				<u> </u>		∢	9
Male with AIDS or documented HIV infection, risk not specifi											-	×L,	0	5
Received transfusion of blood/blood components		o Unknown	-									1 2	<u>×</u> -	9
(other than clotting factor) ' Received transplant of tissue/organs or artificial insemination		 [] 	•			_	sordinator).					1 /	0	3
						. 411 \ 0.000	Janator).				[<u> </u>	X
VII FOR AIRS CASES ON V. D. V. L. V.		ATE/LOCAL				10								
VI. FOR AIDS CASES ONLY—Patient-identifier	ınrormati	on is not ti	ransm					1	Coale! C	u mili - MI	nak.a-			
Patient's name (last, first, MI)				Telej Z	phone n	umber 1		1	Social Sec	urty Nu	mber			
Address (number, street)	City			Сош	ntv/	1			State		ZIP c	occ.		
· ····································	Only			(20)	,						LIF (
DIIS 864 ° P (9/01)						PEC	DIATRIC HI	//AIDS (CONFIDE	NTIAL C	ASE REF	PORT—	Page	1 of 1

VII. Laboratory Data											
HIV Antibody Tests at Diagnosis (Record all test	ts, includ	e earl	iest positi	ve.):						Tes	t Date
						Positive	Negative	Indeterminate	Not done	Month	Year
HIV-1 EIA						\times	U	_	g	0;6	0; 2
HIV-1 EIA						\times	0	_	9	0:7	0:2
HIV-1/HIV-2 combination EIA						1	0	_	9	i	i
HIV-1/HIV-2 combination EIA						1	0	_	9	<u> </u>	-
HIV-1 Western blot/IFA						\times	O	8	g	0:6	0:2
HIV-1 Western blot/IFA						\times	0	8	9	017	012
Other HIV antibody test (specify):						1	0	8	9	1	
HIV Detection Tests (Record all tests, include ea	arliest no	sitive	1				ı			'	
,	•		Test Date								t Date
Positive Negative	1	Mo	nth Yo	ar			Г	Positive Negat		Monto	Year
1 X	g	ļ .			TIIV DNA PCR		t t	1 >		- ! -	
HIV culture 1	9		1	_	HIV DNA PCR		T T	1 🗶) 	<u> </u>	1
HIV antigen test 1	9	<u> </u>			HIV RNA PCR			1 🗡	9	<u>!</u>	1
HIV antigen test 1	9	L :			HIV RNA PCR			1 🗡	. 9		
					Other, (specify):			1 0	> 9	ı	ı
3. HIV Viral Load Test (Record all tests, include earliest Lyae* De ectable Copies/ Lest Lyae* Pes No Copies/ L Z 0 1 3	ml	lectab	Mo	Test Date nth Ye			R (Roche)	13=bDNA Copies/m	(Chiron)	18-Olher Tes Month	t Date Year
4. Immunologic Lab Tests (At or closest to current	_				IIV tes ts w ere not positive o					Van Na	Lielmeum
	Mont	th `	Year		n 18 months of age, does th					Yes No	Unknown g
CD4 count				tna	t would disqualify him/her from	om the AIL)S case o	setinition /	L	1 0	3
CD1 percent				is	aboratory tests were not doc patient confirmed by a physic /-infected	cian as:		Yes N		Date of Do Month	cumentation Year T
·				No	t HIV-infected			1 (9		
									, , , ,		
VIII. Clinical Status (Def. = Definitive dia	gnosis	/ Pr	es Pi	resump	tive diagnosis)						
AIDS Indicator Diseases	Initial Diag	gnosis Pres.	Initia Month	IDate Year	AIDS Indicat	tor Diseases		I	nitial Diagnosi Def. Pres.	s Initia Monto	IDate Year
Bacterial infections, multiple or recurrent (including Salmonella septicemia)	1	NA	1		Kaposl's sarcoma				1 2		l
Candidiasis, bronchi, trachea, or jungs	1	NA	ı		Lymphoid interstitial pn lymphoid hyperplasia	eumonia a	nd/or pul	monary	1 2		
Candidiasis, esophageal	1	2			Lymphoma, Burkitt's (o	r equivajer	nt term)		1 NA		i i
Coccidioidomycosis, disseminated or extrapulmonary	1	NA		<u> </u>	Lymphoma, immunobla	stic (or eq	uivalent t	erm)	1 NA		
Cryptococcosis, extrapulmonary	1	NA	1	İ	Lymphoma, primary in l	brain			1 NA		
Cryptosporidiosis, chronic intestinal								,,		<u> </u>	
(>1 month duration)	1	NA	i	i	Mycobacterium avium of disseminated or extrap		M.Kansa	1811,	1 2	l	'
Cytomegalovirus disease (other than in liver, spleen, or nodes) onset at >1 month of age	1	NA	ı		M. tuberculosis, dissem	inated or e	extrapuln	onary*	1 2	I	ı
Cylomegalovirus relinilis (with loss of vision)	1	2	I		Mycobacterium of other species, disseminated			ified	1 2		
HIV encephalopathy	1	NA	l l		Pneumocystis carinii pr	icumonia	•		1 2		
Herpes simplex: chronic ulcer(s) (>1 month duration); or bronchilis, pneumonilis, or esophagitis, onset at >1 month of age	1	NΛ	1	1	Progressive multifocal I	eukoencer	phalopath	у	1 NA		
Histoplasmosis, disseminated or extrapulmonary	1	NA	I		Toxoplasmosis of brain	, onset at >	>1 month	of ago	1 2	l l	
sosporlasis, chronic intestinal (>1 month duration)	1	NA			Wasting syndrome due	to HI V			1 NA		
Line this shild been dispused with wide-			If was to	Halada				*120.40		<u> </u>	
Has this child been diagnosed with pulmonary tubercul	OSIS?"		If yes, Inl				Year	TRVCIC	ase number		
1 Yes 0 No 9 Unknown			1 Definit	tive	2 Presumptive Da	lo:	- 1				
IX. Provider Information											
	iane numb				's medical record number Perso	on completin	g form		Telephone nu	mber	
Doe, Mary MD (2.	33)5	555	-1234	1- 7	6343-1	Jane	Jone.	5	(233)555	1234
					city your				State	ZIP code	
Address (number, street) 321 Center St.					your	SITY			CA	900	000

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PEDIATRIC HIV/AIDS CONFIDENTIAL CASE REPORT—Page 2 of 4

X. Birth History (For	r PERINAT	AL cas	ses only.)							
Birth history was available for th	is child: [1 Yes	∑ No	9 Unknown	If no	or unknown,	proceed to	Section 2	XI.	
Name of hosp	oita j		Address (number	, street)	City	County	8	State ZIP	code	Country
Hospital at birth:			Cour	nt/		State	ZII' ∞de	Co	untry	
Residence at birth:			Cour	ity		State	Zii code		unuy	
Birth weight	Birth						Neonatal s	status:	Prona	ital Carc
(enter lbs/cz OR grams)	Туре:	1 Sir	ngle 🔼 Twin	1 3 >2	9 Unknown		(99=Unknow	vn)	(99-Uı	nknown/00= None) Months
lbs. oz.	Delivery:	1 Va 4 Ca	ginal 2 Elec esarean, unknow	ntive Caesarean In type	3 Nonelective 9 Unknown	Caesarean	1 Full			n of pregnancy tal care began:
grams	Birth defects: Specify type(s	1 Yees):	s ONo	9 Unknowi Cod			2 Prei	weeks		number of trail care visits:
Did mother receive zidovudine (aduring pregnancy?	was		8 1 2	Unknown 9		ecelve any oti		-		YCS No Unknown '
Did mother receive zidovudine (aduring labor/delivery?	ZDV, AZT)	Ē		Unknown		eceive any oth				Yes No Unknown 9
Did mother receive zidovudine (2 prior to this pregnancy?	•		1 1	9 Unknown	ii yes, specii	у				
Maternal date of birth		Soundex					N	Maternal S	Stato Pati	ient Number
Month Day Year O ! 3 O ! 9 8	0 55	30								
Birthplace of biologic mother	<u> </u>	2 0								
☑ U.S. 7 U.S. Ter	rritories (includir	ig Puerto	Rico) (specify):							
B Other (specify):							9 Unkn o v	vń		
XI. Treatment/Servic	es Referra	ls								
This child received or is receiving	ng:		DATE	STARTED						DATE STARTED
Neonatal zidovudine (ZDV, AZT) for HIV prevention	/	No Unkra	own Month	Day Year	Anti-retrovira HIV treatmer	al therapy for	Yes 1	No U	nknown 9	Month Day Year
Other neonatal anti-retroviral medication for HIV prevention		No Unkno	Month	Day Year	PCP prophyl	axis	Yes	No U	nknown g	Month Day Year 0 8 2 8 0 2
If yes, specify:								•		
Clinic	child has been : cal trial	enro∎ed a	t: Clin	ic		This child				relimbursed by iblic funding
Tes No Ulknowli		2 Other		HRSA-sponsored	2 Other		aic e insurance/HM			rial/government program
3 N	enci	X Unknov	wn 3	None	9 Unknown	3 No co	verage	9	Unknowr	1
This child's primary caretaker is 1 Diologic parent(s) 7 Social service agency	X Otra	er relative	in Section X∎)	=	Føster/adoptive parer Unknown	it, relative	4] Foster/add	optive pare	ent, unrelated
Persons with HIV infection v				<u></u>		ne with condi	tions meeti	na AIDS	. 0366.0	ritaria must he reported
with name. For additional in		_						ilg AIDS	case c	ntena must be reported
XII. Comments										
	1:05.	م ما ل ان،	- atomo al c		0-					
	Mothe	r nefi	uses HTV	grandmoth testing	<u> </u>					
	77,077,0	, , ,	7,000 1,21	19011119						
							_			
DHS 8641 P (9/01)						PEU	IATRIC HIV/AIL	DS CONFIL	DENTIAL C	CASE REPORT—Page 3 of 4

XII.	Comments (continued)
_	
_	

REPORT FORM for HIV-1/2 (Human Immundeficiency Virus type 1/2) ANTIRODY TESTS

DOB: 05/25/19	76				Gender: Male
=	D.# (Do not identify patien		Date Collected	Date Received	State Lab # 85 64 1972
1254-68085	Soundex. Co	de: S530	9/20/02	9/24/02	856417/2
or Patient I.D.#	ed in a IIIV vaccine to	rial? [] Yes		[] Blood [X] Plasma	
	RES	ULTS of LO	CAL LABORATO	RY TESTS	
E IA Kit M fr.	Results O.D.	Cutoff O.D	. IFA Results	Comments:	
Genetic Systems	positive		nonspecific		
	RESULTS of R	EFERENCE	LABORATORY	TESTS	
Enzyme Immune	bassay (EIA)		Immunofluc	prescence (IFA) (1:1	0 dilution)
Average Ratio*	2				
using	netic Systems	kit.		Nonreactive	
				Reactive	
*Ratio = <u>Specimen (</u> Cutoff Opti	Optical Density ical Density			Nonspecific/Unsatisfac	tory
Ratio of 1 or greater Ratio of less than 1					
	SU	PPLEMENT	TAL TESTS PERF	ORMED	
Western blot (1:1	00 dilution)		Radioimmu	noprecipitation Assa	ay (RIPA)
REACTIVE BAND	S PRESENT [] N	ONREACTIVE	REACTIVE B	BANDS PRESENT [NONREACTIVE
[X] p21 [] gp41			[] p24 [] gp41		
[X] gp120 [] gp160			[] gp120		
			[] gp160		
L	NTERPRETATIO	ON of REFE	RENCE LABORA	TORY TEST RES	ULTS
	ody Not Detected				
	ody Detected clusive - See Enclo	osed Note			
	nclosed Note				
				10/03/0	72
100211	lealth Care Provider			Date Repo	rted
456	5 Center Street			Local Labor	
Ariyt	rown, USA 9000			123 Main S Anytown, USA	

Type or Print Submitter's Complete Address

HIV REPORTING BY NON-NAME CODE 75

Phone 1-800-555-1111 Fax 800-555-1212

APPENDIX D: Cross-Referencing Listing Sample

SAMPLE CONFIDENTIAL CROSS REFERENCE LISTING FOR HEALTH CARE PROVIDERS

			I IIEAEIII		,			
Patient Name (Last Name, First Name)	Medical Record #	Soundex	Date of Birth (mm/dd/yyyy)	Gender	SSN# (Last 4 digits)	Lab-generated Report #	Lab Name	Date Reported to LHD
Smith, John	021145	S530	05/25/1982	Male	9092	123456789Q	Health Srvs Agency	10/03/02

APPENDIX E:Soundex Instructions

CREATING A SOUNDEX CODE ELECTRONICALLY

- Office of AIDS has approved electronic Soundexing programs that are available on the DHS/OA website (www.dhs.ca.gov/AIDS) for HTML-, DOS-, and Windows-based programs including Access, Excel, SAS, and JavaScript. The Office of AIDS encourages laboratories to use the electronic system, if possible, to eliminate the possibility of error. (Laboratories that cannot access these macros via the Internet may request a diskette version from their local health department.)
- Soundexing is only done for the patient's last name (surname). If the patient has a hyphenated last name, type the full hyphenated name, omitting the hyphen and the correct Soundex code will be displayed.
- Soundex codes can be created electronically or manually. Generating a Soundex code electronically is preferable for a couple reasons:
 - ✓ It is much easier, saving time and resources.
 - ✓ It is more accurate because it is less prone to human error.
- On the next page are the instructions for manually creating a soundex code.
 Note the disparity between the instruction for manual Soundex code creation and electronic Soundex code creation. Electronic Soundexing is the way to go.

State of California—Health and Human Services Agency

Department of Health Services Office of AIDS HIV/AIDS Surveillance Program

SOUNDEXING INSTRUCTIONS

The purpose of soundexing is to facilitate matching and unduplicating reported HIV and AIDS cases. The soundex code maintains the confidentiality of reported cases by converting the last name of an individual to an index letter and a three-digit number. In coding by this system, the index letter is the first letter of the last name and the subsequent letters are converted to a numeric code in accordance with the following general rules:

Rule			
Number	Instructions	Example	
1	The first letter of the last name is never coded.		
2	The vowels A, E, I, O, U, and Y are never coded.		
3	The consonants H and W are never coded.		
4	Key letters and their equivalents are converted to code numbers.		
	Key Letter Equivalents Code Number		
	B B, F, P, V 1		
	C C, G, J, K, Q, S, X, Z 2		
	D D, T 3		
	L L 4 M M, N 5		
	M M, N 5 R R 6		
		HOLMES	11450
5	The consonants of the last name, other than the first letter and H and W, are converted to their respective code numbers in the order in which they appear	HO <u>LM</u> E <u>S</u> 45 2	H452
	in the name.	GWI <u>LF</u> OY <u>L</u> E	G414
	in the halle.	41 4	0111
6	The numeric code always consists of three digits. The codes for names which	G RAHAM	G650
	do not contain three key letters or their equivalents are completed by adding	6 5	
	zeros.	B AI <u>L</u> EY	B400
	Note that the zeros follow the assigned number code.	4	
		SHAW	S000
7	The soundex code for names that contain more than three key letters, or their	VO <u>ND</u> E <u>RL</u> EH <u>R</u>	V536
	equivalents, are complete when a three-digit numeric code has been assigned.	53 64 6	
8	Two or more key letters, or their equivalents, appearing together are treated as	BALLOU	B400
	one key letter and are assigned one number.	4-	1050
		JA <u>CKS</u> O <u>N</u> 2 5	J250
9	A key letter, or its equivalent, immediately following an initial letter (first letter	SCANLON	S545
· ·	of the last name) of the same group or value is not coded.	- 54 5	0010
	3	<u>SCKL</u> A <u>R</u>	S460
		4 6	
10	Key letters, or their equivalents, separated by A, E, I, O, U, or Y are coded	HA <u>NN</u> O <u>N</u>	H550
	separately.	5- 5	
		S A <u>LK</u> IEWI <u>CS</u>	S422
		42 2-	
11	Key letters, or their equivalents, separated only by the letter W or the letter H	SOKWZY	S200
	are coded as one key letter. Note that in the name Schkolnik, the C is not coded because it is in the group	2 – S CHKOLNIK	S452
	equivalent to the letter S, and the first K is not coded because it is in the group	<u>3011KOLNIK</u> – – 45 2	3432
	equivalent to the letter C, from which it is separated only by an H.	10 2	
12	Abbreviated prefixes such as Mc or St. are coded as if spelled out.	MCKILHAN = MACKILHAN	M245
		2- 4 5	
		ST. JOHN = SAI <u>NT</u> <u>J</u> OH <u>N</u>	S532
		532 –	
13	An apostrophe or hyphen in a name is disregarded.	O' <u>N</u> EI <u>LL</u>	O540
		5 4-	1507
		JAMES-WALKER	J524
		5 2 4	

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	L L 4 M M, N 5		
	M M, N 5 R R 6		
		HOLMES	LIAFO
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	in the name.	GWI <u>LF</u> OY <u>L</u> E	G414
	in the halle.	41 4	0111
6	The numeric code always consists of three digits. The codes for names which	G RAHA <u>M</u>	G650
	do not contain three key letters or their equivalents are completed by adding	6 5	
	zeros.	B AI <u>L</u> EY	B400
	Note that the zeros follow the assigned number code.	4	
		SHAW	S000
7	The soundex code for names that contain more than three key letters, or their	VO <u>ND</u> E <u>RL</u> EH <u>R</u>	V536
	equivalents, are complete when a three-digit numeric code has been assigned.	53 64 6	
8	Two or more key letters, or their equivalents, appearing together are treated as	BALLOU	B400
	one key letter and are assigned one number.	4-	1250
		JA <u>CKS</u> O <u>N</u> 2 5	J250
9	A key letter, or its equivalent, immediately following an initial letter (first letter	SCANLON	S545
· ·	of the last name) of the same group or value is not coded.	- 54 5	0010
	3	S CKLAR	S460
		4 6	
10	Key letters, or their equivalents, separated by A, E, I, O, U, or Y are coded	HA <u>NN</u> O <u>N</u>	H550
	separately.	5- 5	
		S A <u>LK</u> IEWI <u>CS</u>	S422
		42 2-	
11	Key letters, or their equivalents, separated only by the letter W or the letter H	SOKWZY	S200
	are coded as one key letter. Note that in the name Schkolnik, the C is not coded because it is in the group	2 - S CHKOLNIK	S452
	equivalent to the letter S, and the first K is not coded because it is in the group	45 2	0402
	equivalent to the letter C, from which it is separated only by an H.		
12	Abbreviated prefixes such as Mc or St. are coded as if spelled out.	MCKILHAN = MACKILHAN	M245
		2- 4 5	
		ST. JOHN = SAINT JOHN	S532
		532 –	
13	An apostrophe or hyphen in a name is disregarded.	O' <u>N</u> EI <u>LL</u>	O540
		5 4-	1504
		JA <u>M</u> E <u>S</u> -WA <u>L</u> KER 5 2 4	J524
		J Z 4	

DHS 8641 SC (9/01)

APPENDIX F:

Manual and Electronic Laboratory Reporting to Local Health Departments

NOTIFICATION OF CONFIRMED HUMAN	ED HUMAN	LABOR (Specimen A	LABORATORY REPORT NUMBER (Specimen Accession Number or Other Unique Specimen Identifier)	NUMBER pecimen Identifier)
IMMUNODEFICIENCY VIRUS (HIV) TEST	(HIV) TEST		85641972	
RESULT BY LABORATORY TO	RY TO	DATE SPECIMEN TESTED		0 9 2 4 2 0 0 2
LOCAL HEALIH DEFAKTIVIEN L(((6,210))	(06/2002)	LABORATORY FINDINGS		-
SOUNDEX DATE OF BIRTH	GENDER	A, IIIV ANTIBODY I	A, HIV ANTIBODY TEST AT DIAGNOSIS	Positive
5 5 3 0 0 5 2 5 1 9 7 6	X(1) Mole (2) Econolis	• IIIV-1 EIA	• IIIV-1 EIA	Ø
(Corribets only 1: provicer carbot release patient s last name or sounders ones) PATIENT'S CODE #:		• HIV-1/HIV-2 co	• HIV-1/HIV-2 combination EIA	
DATE SPECIMEN WAS COLLECTED		• HIV-1 Western	• HIV-1 Western Blot/IFA	図
0 9 2 0 2 0 0 2	M-F D@F-M	• Other HIV anti	Other HIV antibody test	
PROVIDE R :		Specify:		
vom: Local Health Care Provider	ider	B. POSITIVE HIV DETECTION TEST	TECTION TEST	
ANDRESS 456 Center St		⊠ Culture	□ Antigen □ PCR,	JPCK, DNA, or RNA probe
	STA 48000	□ Other		
PHONE (888) 555-2222		Specify:		
LABORATORY: C	8 0 0 R 2 4 9 8 3 0 5 C.VIRALLOAD TEST	C. VIRAL LOAD TES	T	
NAME Local Laboratory		Result		
rss 123 Center St.	_	Únits	□ copies/mL	□ log(10)copies/mL
cny Anytown Sta	STAICA 40000	Test type	☐ (11) NASBA (Organon)	(12) RT-PCR (Roche)
PHONE (\$88) 555-1111			(13) bD.N.4 (Bayer)	(18) Other

INSTRUCTIONS FOR SUBMITTING CONFIRMED HUMAN IMMUNODEFICIENCY VIRUS (HIV) TEST* RESULTS <u>ELECTRONICALLY</u> BY LABORATORY TO LOCAL HEALTH DEPARTMENT (06/2002)

HIV/AIDS CASE REGISTRY OFFICE OF AIDS DEPARTMENT OF HEALTH SERVICES (DHS)

When submitting confirmed HIV test results electronically to local health jurisdictions, the following <u>must be</u> followed:

- 1) The file format must be MSDOS/Windows ASCII.
- 2) Each file should be named with an abbreviation of the submitting laboratory name, followed by the date of submission of the form **yyyymmdd**, and with the file extension **txt**.

Example: MYLAB20020529.TXT.

- 3) Each file contains records, and each record represents **one** test result.
- 4) Each record consists of fields.
 - a) Fields within a record are delimited by the pipe "|" symbol.
 - b) This means that **NO DATA** can contain the symbol "|" as it is reserved for delimiting fields.
 - c) A delimiter does not precede the first field and a delimiter does not follow the last field.
 - d) Missing or unknown values are represented with a single period ".".
 - e) Telephone numbers must include area codes.
- 5) It is highly encouraged that, whenever possible, each line in a file represents one record. The lines in each file end with the line-feed carriage-return that is typical of MSDOS and Windows.
- 6) In situations where the total length of a particular record exceeds the maximum logical record length permitted by your host system, then the record can span multiple lines and:
 - a) Each line (except the last line) within that record must end with a **continuation character** "+", the plus symbol.
 - b) The line that ends with the line-feed carriage-return and without the continuation character "+" is the end of the record.
 - c) When doing this, one must be careful that the line ends with a "+" symbol **ONLY** when it is a continuation and not because the data itself ends with a plus "+".

7) The first record of each file must contain the following fields:

FIELD No.	FIELD NAME	FIELD DESCRIPTION	
1	LAB_NAME	Name of submitting laboratory (as shown on license)	
2	LAB_CLIA	15-digit Clinical Laboratory Improvement Amendments (CLIA) certificate number of submitting laboratory	
3	LAB_STREET	Street address of submitting laboratory	
4	LAB_CITY	City where submitting laboratory is located	
5	LAB_ST	State where submitting laboratory is located	
6	LAB_ZIP	Zip code of submitting laboratory	
7	LAB_PHONE	Phone number of appropriate contact person at the submitting laboratory	

8) Test result records should begin on the second record of each file. The fields are as follows:

FIELD No.	FIELD NAME	FIELD DESCRIPTION	CODING INSTRUCTIONS
1	SOUNDEX	Soundex code of patient's surname	Follow the coding instructions for soundex
	ВТНМО		January 01
			February 02
			March 03
			April 04
			May 05
		B	June 06
2		Patient's month of birth	July 07
			August 08
			September 09
			October 10
			November 11
			December 12

FIELD No.	FIELD NAME	FIELD DESCRIPTION	CODING INSTRUCTIONS
3	BTHDAY	Patient's day of birth	01 - 31
4	BTHYR	Patient's year of birth	4-digit year
5	GENDER	Patient's gender	Male 1 Female 2 M – F 3 F – M 4
6	CODE_BY_PVD	Patient's code assigned by provider (complete if provider cannot release patient's last name or soundex code)	
7	CLIENT_ID	The 8-digit California State DHS Client ID Number (provided only on the Confidential HIV Antibody Test lab slip – DHS 8257C (1/02))	
8	LAB_NO	Laboratory report number (specimen accession number or other unique specimen identifier)	
9	SP_COL_MO	Month specimen was collected	Same as BTHMO
10	SP_COL_DAY	Day specimen was collected	01 - 31
11	SP_COL_YR	Year specimen was collected	4-digit year
12	SP_TST_MO	Month specimen was tested	Same as BTHMO
13	SP_TST_DAY	Day specimen was tested	01 - 31
14	SP_TST_YR	Year specimen was tested	4 digit year
15	TEST_NAME	Name of laboratory test performed	
16	TEST_CODE	Code for laboratory test performed	If available, use Logical Observation Identifiers Names and Codes (LOINC); otherwise use code assigned by the laboratory

FIELD No.	FIELD NAME	FIELD DESCRIPTION	CODING INSTRUCTIONS
17	RESULT	Result of laboratory test performed	
18	RESULT_CODE	Code for laboratory test result	If available, use Systemized Nomenclature of Medicine (SNOMED); otherwise use code assigned by the laboratory
19	UNITS	Units of laboratory test result	
20	PVD_NAME	Name of healthcare provider who submitted the specimen	
21	PVD_STREET	Street address of healthcare provider who submitted the specimen	
22	PVD_CITY	City where healthcare provider who submitted the specimen is located	
23	PVD_ST	State where healthcare provider who submitted the specimen is located	
24	PVD_ZIP	Zip code of healthcare provider who submitted the specimen	
25	PVD_PHONE	Phone number of healthcare provider who submitted the specimen	
26	FAC_NAME	Name of facility that submitted the specimen	
27	FAC_STREET	Street address of facility that submitted the specimen	
28	FAC_CITY	City where the facility that submitted the specimen is located	
29	FAC_ST	State where the facility that submitted the specimen is located	
30	FAC_ZIP	Zip code of facility that submitted the specimen	
31	FAC_PHONE	Phone number of facility that submitted the specimen	
32	UPDT_FLAG	Indicator of whether current report is an update of a previously reported test result with missing or incorrect data	New report 0 Update 1

9)	Since the file contains no identifying information of the patient, the file should be stored on a 3.5" diskette and mailed to the local health jurisdiction in which the health care provider is located on a weekly basis.

(b) all tests used to monitor HIV infection, including HIV nucleic acid detection.

5

^{* &}quot;Confirmed HIV test" means:

⁽a) a procedure which verifies the presence of HIV infection as determined by any clinical laboratory test or examination used to detect the presence of HIV, a component of HIV, or antibodies to or antigens of HIV, including the HIV antibody (HIV-Ab), HIV p-24 antigen, Western blot (Wb), and immunofluorescence antibody tests; or

APPENDIX G: California Health Department HIV/AIDS Surveillance Contacts

Note: This list of local health department Surveillance Contacts is current as of August, 2002. Updates to this list can be found on the California Department of Health Services Office of AIDS website at www.dhs.ca.gov/aids.

(*)indicates primary contact person

ALAMEDA COUNTY HEALTH CARE SERVICES AGENCY PUBLIC HEALTH DEPARTMENT, DIVISION OF AIDS & COMMUNICABLE DISEASE

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David Tucker 510.208.1271
Unit Phone 510.268.2372

ALPINE COUNTY HEALTH DEPARTMENT

P. O. Box 548

75 B Diamond Valley Road Markleeville, CA 96120 FAX: 530.694.2770

*Lynette Bennett E-mail: lbennett@alpinecountyca.com 530.694.2146

AMADOR COUNTY HEALTH DEPARTMENT

1003 Broadway, Suite 203 Jackson, CA 95642 FAX: 209.223.1562

*Janet Caccia E-mail: jcaccia@co.amador.ca.us 209.223.6407

CITY OF BERKELEY PUBLIC HEALTH DEPARTMENT

2344 Sixth Street Berkeley, CA 94710 FAX: 510.981.5345

*Jose A. Ducos E-mail: jducos@ci.berkeley.ca.us 510.981.5281 Ramsey Ramos E-mail: rramos@ci.berkeley.ca.us 510.981.5343

BUTTE COUNTY PUBLIC HEALTH DEPARTMENT

695 Oleander Avenue Chico, CA 95926 FAX: 530.891.2873

*Eric Sawtelle (in Chico) E-mail: esawtelle@buttecounty.net 530.895.6565

(Oroville) 530.538.6109

Note: Address mail for Eric to:

Butte County Public Health Dept., 202 Mira Loma Drive, Oroville 95965

Charlotte Freer E-mail: cfreer@buttecounty.net(Oroville) 530.538.6220

(Oroville FAX) 530.538.6221

CALAVERAS COUNTY PUBLIC HEALTH DEPARTMENT

Government Center 891 Mountain Ranch Road San Andreas, CA 95249 FAX: 209.754.6459

*Jill Sullivan E-mail: jsullivan@co.calaveras.ca.us 209.754.6523

General Information 209.754.6460

COLUSA COUNTY DEPARTMENT OF HEALTH & HUMAN SERVICES PUBLIC HEALTH DIVISION

251 East Webster Street Colusa, CA 95932 FAX: 530.458.4136

*Martha Dragoo (Acting) E-mail: mdragoo@ncen.org 530.458.0380

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Martinez, CA 94553 FAX: 925.313.6344

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FAX: 530.626.4713

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Communicable Disease 1221 Fulton Mall P. O. Box 11867 Fresno, CA 93775

FAX: 559.445.3255

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*Grinnell Norton E-mail: gnorton@glenncountyhealth.net 530.934.6588

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*Suzanne Stoutenburg E-mail: sstouhhs@qnet.com 760.873.3914

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1800 Mt. Vernon Ave. Bakersfield, CA 93305-4198

FAX: 661.868.0171

*Dave Martin E-mail: martind@co.kern.ca.us 661.868.0366 Mary Hutson 661.868.0491

KINGS COUNTY PUBLIC HEALTH DEPARTMENT

Communicable Disease Program 330 Campus Drive Hanford, CA 93230 FAX: 559,582,0927

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*Joanna Zimmermann, P.H.N. E-mail:

530.251.8384

CITY OF LONG BEACH DEPARTMENT OF HEALTH & HUMAN **SERVICES**

2525 Grand Avenue, Room 201 Long Beach, CA 90815

FAX: 562.570.4374

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MARIPOSA COUNTY PUBLIC HEALTH DEPARTMENT

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Mariposa, CA 95338 FAX: 209.966.4929

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MODOC COUNTY DEPARTMENT OF HEALTH SERVICES

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MONO COUNTY HEALTH DEPARTMENT

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Mammoth Lakes, CA 93546

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NAPA COUNTY HEALTH & HUMAN SERVICES AGENCY

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Santa Ana, CA 92706 FAX: (714) 834-8526

714.834.8124 *Brandon Page E-mail: bpage@hca.co.orange.ca.us Arthur Thompson E-mail: thompsonarthur@hca.co.orange.ca.us 714.834.8126

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SIERRA COUNTY HEALTH DEPARTMENT

202 Front Street

P.O. Box 7

Loyalton, CA 96118 FAX: 530.993.6741

*Janis Hardeman, R.N., P.H.N. E-mail: jhschs@psln.com 530.993.6705

SISKIYOU COUNTY PUBLIC HEALTH

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*Blair Loftus, R.N., PHN E-mail: bloftus@co.siskiyou.ca.us 530.841.4059

or; 1.800.442.2333

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355 Tuolumne Street Vallejo, CA 94590 FAX: 707.553.5649

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COUNTY OF SONOMA DHS, PUBLIC HEALTH DIVISION

625 Fifth Street

Santa Rosa, CA 95404-4428

FAX: 707.565.4401

Patricia Ensrud (AIDS cases) E-mail: pensrud@sonoma-county.org 707.565.4580 *Susan Timko (HIV cases) E-mail: stimko@sonoma-county.org 707.565.4533

STANISLAUS COUNTY HEALTH DEPARTMENT

820 Scenic Drive Modesto, CA 95350 FAX: 209.558.7531

Jean YokotobiE-mail: jyokotobi@schsa.org209.558.4800*Maribel LopezE-mail: mlopez@schsa.org209.558.8052

SUTTER COUNTY DEPARTMENT OF HUMAN SERVICES

1445 Circle Drive

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Yuba City, CA 95991 FAX: 530.822.7223

General Information 530.822.7215

*Alice Williams-Root E-mail: AWilliamsRoot@co.sutter.ca.us 530.822.7215

TEHAMA COUNTY HEALTH AGENCY

1860 Walnut Street Red Bluff, CA 96080 FAX: 530.527.0362

*Sydnei Wilby 530.527.6824 Virginia Sandberg E-mail: sandbergv@tcha.net 530.527.8491 X3618

TRINITY COUNTY HEALTH & HUMAN SERVICES DEPARTMENT

No. 1 Industrial Park Way

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Weaverville, CA 96093 FAX: 530.623.1297

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VENTURA COUNTY PUBLIC HEALTH SERVICES

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